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ABSTRACT

This bulletin issue contains seven papers describing innovations in various areas of special education and rehabilitation. "Training Criminal Justice Personnel To Recognize Offenders with Disabilities" (Keith L. Curry and others) examines prevalence figures of disabilities among incarcerated adults and describes the "Effectively Communicating with Handicapped Offenders" training program. "Preparation of Families for Incidental Teaching and Advocacy for Their Children with Autism" (Gail G. McGee and others) points out that family supports may be most effective when parents can participate in designing an individualized program tailored to their unique family needs. "Serving the Needs of Children with AIDS and Their Families" (Geneva Woodruff) describes families' needs and types of programming that meet families' needs, focusing on Project STAR. "Serving Students with Emotional and Behavioral Disorders through a Comprehensive Community-Based Approach" (Michael H. Epstein and others) addresses issues and strategies involved in developing integrated services. "Transition Planning for Individuals Who Are Deaf and Blind: A Person-Centered Approach" (Phyllis Perlroth and others) describes the "Transition Occupational Placement for Students" project. "True or False? Truly Collaborative Relationships Can Exist between University and Public School Personnel" (Terri Vandercook and others) defines characteristics for collaboration. "Early Childhood Community Integration: An Option for Preschool Special Education" (Mary Beth Bruder) describes the Early Childhood Special Education Community Integration Project at the Pediatric Research and Training Center of the University of Connecticut School of Medicine. (JDD)

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

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Winter 1993 *Volume V, Number 3*

Innovations
in Special Education and Rehabilitation

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Office of Educational Research and Improvement
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UNITED STATES DEPARTMENT OF EDUCATION

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Richard W. Riley Joins Department as Secretary of Education

On December 21, 1992, President Bill Clinton nominated Richard Wilson Riley for the post of U.S. Secretary of Education. After confirmation hearings, during which many Senate committee members expressed their unequivocal support of his nomination, Riley was confirmed by unanimous consent on January 21, 1993. Riley was sworn in as the sixth Secretary of Education on January 22, 1993.

Dick Riley was born in Greenville County, South Carolina on January 2, 1933. He received a bachelor's degree cum laude in political science from Furman University in 1954. He served for two years as an officer on a mine-sweeper in the United States Navy. In 1959, Riley received his law degree from the University of South Carolina School of Law. He served as legal counsel to the Judiciary Committee of the United States Senate until he joined his family's law firm in 1960. Before becoming governor in 1978, Riley served as a South Carolina state representative from 1963 to 1967, and from 1967 to 1977 as state senator.

In 1980, the people of South Carolina voted to amend the state constitution, which enabled Riley to be the first person in modern South Carolina history to run for a second term as governor. In 1982, he was re-elected to a second four-year term.

As governor of South Carolina, Riley made an indelible mark on public education and gained a national reputation as a leader in the area of quality education reform. He initiated and led the fight for the Education Improvement Act (1984), which, according to a Rand Corporation study, was the most comprehensive education reform measure in the country. He was a nationally recognized leader in the areas of public education reform, nuclear waste disposal, and preventive health care. His administration was marked by conservative fiscal management of government and remarkable progress in job development, quality education, aggressive protection of the environment, and improved health care for all people. In a 1986 *Newsweek* poll of the nation's governors, Governor Riley was ranked the third most effective governor by his colleagues.

Dick Riley has received a number of state and national awards including, three times, the South Carolina Education Association's Friend of Education Award, the 1983 Government Responsibility Award from the Martin Luther King, Jr. Center, and the 1981 Connie Award for special conservation achievement by the National Wildlife Federation. Riley has also served on numerous boards and commissions, including the National Assessment Governing Board, the Carnegie Foundation Task Force on Meeting the Needs of Young Children, and the Duke Endowment. In 1990, Riley served as an Institute Fellow at the John F. Kennedy School of Government at Harvard University.

Before joining the Clinton Administration, Riley was a senior partner with the South Carolina law firm of Nelson, Mullins, Riley & Scarborough. He is married to the former Ann Osteen Yarborough. They have four children. ♦

Innovations
in Special Education and Rehabilitation

Volume V, Number 3
Winter 1993

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Secretary
United States Department of Education

William L. Smith
Acting Assistant Secretary
Office of Special Education and Rehabilitative Services

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Cover photo
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Training Criminal Justice Personnel to Recognize Offenders with Disabilities

Keith L. Curry, Ph.D.

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Introduction

One needs only to read the daily newspaper to see that the growth in the rate of individuals who have been arrested and sentenced is climbing at a higher rate than the available cells in local, county, state, or federal correctional facilities. Most correc -n-al facilities at all levels are at or above capacity, with occupancy rates ranging from 100 to 150 percent. The numbers in Table 1 reflect *adult* prison population growth over the past twenty years and are also indicative of the recent surge in jail and prison construction.

Number Incarcerated in Federal and State Facilities

1970	**196,429**
1980	**315,974**
1988	**581,609**
As of December, 1991	
• State facilities	**751,806**
• Federal facilities	**71,608**
• Local, city, and county facilities	**422,609**
Current Total	**1,246,023**

These figures reflect a 28 percent increase in adult facilities since December 1988. Equally alarming is documentation that in 1987, the latest year for which there are figures, there were 91,646 individuals held in public and private *juvenile* facilities. This figure is undoubtedly approaching 100,000 at this date, with the percentage increase in juvenile facilities paralleling that in adult facilities.

According to 1990 figures from the U.S. Department of Justice, more than 79 percent of all new admissions to prisons in the United States are under 35 years of age; 37.5 percent are 24 years and under; and the median age of all admissions is 27 years. (*Sourcebook of Criminal Justice Statistics*, 1990, K. Maguire and T. Flanagan, Eds.). There is a growing trend to incarcerate in adult prison facilities youth under 18 years of age who have committed serious crimes. There has also been a significant increase in the number of females incarcerated. In addition to the 1,236,023 incarcerated, there are 2,670,234 individuals on probation and parole.

Jail and prison overcrowding is of prime concern in most states, both from a humane and from an economic standpoint. Overcrowded conditions coupled with the severe budget cutbacks in most states frequently result in a warehousing atmosphere, with a decrease in educational programming and an increase in facility violence. It has become clear to professionals, both in special education and in corrections, that thousands of individuals with disabilities reside within the local, state, and federal prisons and jails.

The Problem

Prevalence figures on incarcerated adults with retardation have ranged from 3.6 percent to 30 percent (Brown and Courtless, 1971; Smykla and Willis, 1981; Santamour and West, 1979; and Rockowitz, 1985). If individuals with learning disabilities were included in those studies, the prevalence of incarcerated individuals with disabilities would be much higher. The prevalence of incarcerated *youth* with disabilities ranges from 12 percent to 70 percent according to Hockenberry (1980) and Murphy (1986). Rutherford, Nelson, and Wolford (1985) estimated that the average number of offenders with disabilities in state juvenile correctional programs was 28 percent, with 10 percent the average in state adult correctional facilities. According to the Criminal Justice Sourcebook cited above, more than 62 percent of admissions to prisons are African American or Hispanic.

From 1985 to 1987 the authors screened 1,716 individuals in local jails in Erie and Niagara counties in New York (Development Disabilities/Criminal Justice Project) and found, conservatively, that 5.3 percent were mildly retarded, with very strong evidence of at least another 5 percent being learning disabled. Of those diagnosed as having disabilities, 98.9 percent were school dropouts. More than 66 percent were reading at or below the second grade level. The individuals identified with disabilities in the DD/CJ Project had arrest records ranging from 1 to 30 priors. Without intervention, they were destined to continue to pass through the revolving door of the jail and prison system again and again.

Using a conservative prevalence figure of 10 percent and extrapolating it to the national adult prison population, one could estimate that nationwide approximately 120,000 incarcerated individuals have disabilities and that approximately 45,000 of them are 24 years of age or younger. The primary disabling conditions included in this number are mild retardation and learning disabilities, which are often "hidden" disabilities. Using the same 10 percent figure, one would expect to find another 260,000 individuals with disabilities on probation and parole. Additionally, there are probably another 28,000 youth with disabilities in juvenile facilities. Excluded from these disability figures are those whose primary problem is some form of serious emotional disturbance.

From our experience, we know the following about offenders who are mildly retarded or learning disabled when they encounter the criminal justice system.

- They are unrecognized at first contact because the offender with mild retardation or learning disabilities has no physical anomaly and often is verbal enough to give the impression of being nondisabled.
- They often have a desire to please authority figures or peers, resulting in a vulnerability to suggestion. They are often talked into committing a crime; are still on the crime scene when authorities arrive; confess whether guilty or not, saying what they think a person wants to hear. While incarcerated, they are prone to be victims—socially, sexually, and economically.
- They are most often arrested for petty "nuisance" crimes over and over again, clogging up an already overcrowded system.
- They have limited ability to assist in their defense. There is little or no plea bargaining to reduce charges, therefore, they are convicted of the offense for which they were arrested, unlike most other detainees.
- Lack of response is often misconstrued as defiance or noncompliance, thus they are often given longer sentences than nondisabled peers for the same crime.
- Appeals are sought less frequently, and post conviction relief is requested in very few cases.
- They are considered poor prospects for probation and other alternatives to incarceration, despite evidence that this type of sentence is more effective for them in reducing recidivism.

Courtesy Ken Curry

- While incarcerated, they have difficulty adjusting to routine and learning regulations, thereby accumulating rule infractions and write ups. This lessens their chances for extra canteen, extra free time, a choice job, a good cell, or time off for good behavior while in the institution, and lessens their chance for parole.
- They rarely take part in rehabilitative work or education programs, often because programs offered are not appropriate for those individuals who are learning disabled or mildly retarded, and also because of their desire to "pass" as normal. As a result, most of their time in prison is spent in menial tasks or meaningless activity.

It is obvious from the sheer numbers of those with disabilities who are in the criminal justice system that education is needed to help professionals recognize mildly retarded and learning disabled individuals, to interact effectively with them, and to deal with them more appropriately when they are incarcerated. In fact, many criminal justice system professionals are actively seeking assistance in managing a population for which they have had no training. There is also a need to begin to formulate transition plans to the agencies before release and to prepare criminal justice personnel to refer individuals to community agencies upon release.

Project Design

In 1987–90, with funding from the U.S. Department of Education's Office of Special Education and Rehabilitative Services, the authors developed materials that were designed for preservice and in-service education for corrections, law enforcement, sheriffs' departments, youth counselors, probation officers, and others in the criminal justice system. The Effectively Communicating with Handicapped Offenders (ECHO) training materials consist of eight videotapes, each with a supporting manual.

Subsequent to the development of the ECHO materials in 1990, funding was received from the Office of Special Education and Rehabilitative Services to disseminate the materials to train criminal justice personnel in 15 states over a three-year period. ECHO is a train-the-trainer program consisting of four days of training on mild retardation and learning disabilities, and a specific type of serious mental illness. State leadership personnel in criminal justice fields arrange for and facilitate ECHO training, and choose key trainers in corrections, youth facilities, sheriffs' departments, and law enforcement to participate. The ECHO Project provides each central office professional and each trainer completing the program with a set of the training materials for his or her facility or agency. In return, these trainers make a commitment to use the materials to train rank and file personnel in their unit. The number of all individuals trained, along with evaluative data, is entered into a data base.

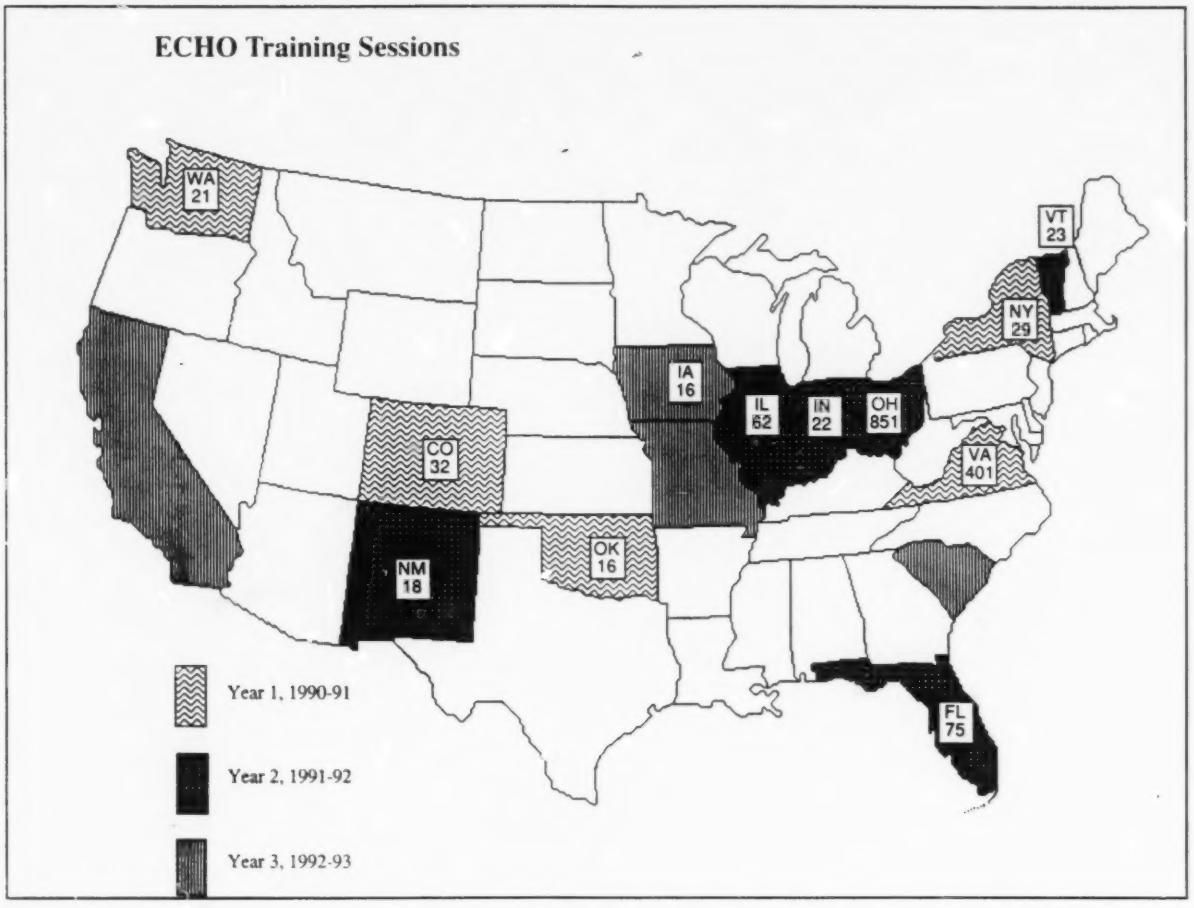
Figure 1 shows the states where training has taken place in the first two years and the number of professionals trained in each state. With the assistance of the New Mexico Developmental Disabilities Planning Council, training was conducted in an eleventh state in the second year. The map also shows the states that have committed to training in the third and final year of the project. Training has already occurred in Iowa. Because of the size of the state, two trainings will be held in California.

The purposes of the ECHO training and dissemination are to:

- increase the ability of criminal justice personnel to recognize the characteristics of individuals with mild retardation or learning disabilities;
- increase the ability of criminal justice personnel to differentiate between individuals with mild retardation, those with learning disabilities, and those with serious mental illnesses;
- improve the ability of rank and file criminal justice personnel to interact effectively with and manage individuals with disabilities; and
- increase the referrals of those with suspected disabilities to programs within the corrections system and to community agencies upon release.

Findings

The evaluation questions upon which ECHO Project data are being gathered are:



Evaluation Question 1:
Did the activities occur as proposed?

Evaluation Question 2:
How many central office/leadership personnel were trained by the project staff each year?

Evaluation Question 3:
How many trainers were trained in the use of ECHO training modules during each year of the project in each participating site?

Evaluation Question 4:
How many criminal justice personnel were trained by the trainers each year at each participating site?

Evaluation Question 5:
Was the training provided to the site central office/administrative personnel effective?

Evaluation Question 6:
How effective was the training provided to the trainers at each site?

Evaluation Question 7
To what extent did the training provided to criminal justice personnel at each site affect the identification of individuals with disabilities?

Evaluation Question 8:
To what extent did the training provided to criminal justice personnel affect their interactions with individuals with disabilities?

At each training session held by the authors, all participants are asked to evaluate the materials and the presentations. To put evaluation of the sessions and the materials in better perspective, it should be noted that the evaluators are, for the most part, from paramilitary organizations, have no background in disabilities, are resistive, sometimes almost hostile, at the beginning of the training sessions, but are enthusiastic supporters by the end of the fourth day. While attitudes are always difficult to change, preliminary data indicate the training sessions have been effective.

The training has been very successful and very productive from an education standpoint. An additional benefit is that the training has also been instrumental in initiating and fostering networking between the criminal justice agencies and community agencies serving those with disabilities. The ECHO training sessions have been attended by individuals from a wide variety of disciplines in criminal jus-

tice, all of whom are eager to interact with other professionals to alleviate common areas of concern. Professions represented at sessions held to date have included the following:

- *corrections officers*
- *correctional educators*
- *law enforcement officers*
- *correctional counselors*
- *sheriffs' deputies*
- *social workers*
- *probation officers*
- *psychologists*
- *youth counselors*
- *corrections nurses*
- *police psychologists*
- *hostage negotiators*
- *case managers*
- *criminal justice*

This networking has given rise to the beginning of programs to transition individuals with disabilities successfully from prison to communities.

Evaluation questions 7 and 8 ask whether line staff trained have actually improved their interactions with offenders with disabilities and whether they have begun to identify and refer. Questionnaires developed by the project relating to evaluation questions 7 and 8 have been shared with those already trained. Because it takes from six to twelve months' advance notice for the trainers to schedule their sessions in the training academies, no data on these critical questions have yet been received, but data are expected sometime this year.

One comment voiced by professionals in the developmental disabilities field is that the materials sometimes deviate from currently used "person first" terminology. This is valid, since the materials were developed prior to the adoption of person first terminology as the standard.

Conclusions and Recommendations

Leadership personnel in law enforcement, corrections, divisions for youth, and probation are very receptive and even anxious to receive information on how to identify offenders with mild retardation and learning disabilities. The Effectively Communicating with Handicapped Offenders (ECHO) materials and training have been very well received in the eleven states in which training has taken place. It remains to be seen to what degree line staff will act on their training and increase their identification and referral of those offenders suspected of having disabilities. It is clear that prior to the ECHO training in the 11 states, there was little or no identification of people who are mildly retarded or learning disabled in corrections, law enforcement (including the courts), or probation and parole. Thus, appropriate education programs were minimal or nonexistent. There was little transitional planning for post release to the communities, and few community service agencies were involved with the offender after release.

These situations can improve only if the offender with disabilities is identified early and at every stage in the criminal justice system. The ECHO training and dissemination project will have made this possible in 15 states by the end of 1993. More education on mild retardation and learning disabilities is needed at every level of the criminal justice system. Human service agencies must be encouraged to provide service to this population and to assist corrections, the courts, probation, and parole in transitioning individuals into meaningful community education and vocational pursuits. Appropriate educational and vocational training programs must be established in correctional settings. Of course, targeting youth with disabilities who are at risk of becoming offenders while they are still in school could deter many from entering the criminal justice system in the first place. At $25,000 to $30,000 per year to support a person in incarceration, and $100,000 to build a cell, it would seem fiscally and socially sound to expand these pursuits.

NOTES

From the U.S. Department of Justice, collected from a National Jail Inmate Survey and the National Prisoner Statistic Reporting System, in cooperation with the Federal Bureau of Prisons.

Two terms commonly used in criminal justice systems are "training," to describe education, and "management," to describe interactions with inmates.

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Preparation of Families for Incidental Teaching and Advocacy for Their Children with Autism

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Courtesy Gail McGee

An "incidental teaching" family program was developed to intensify preschool intervention for young children with autism, and to encourage early empowerment for their parents. Incidental teaching procedures consist of systematic instruction that is provided in the context of naturally-occurring activities, and the young recipients play a central role in determining the timing, context, and topics of instruction (McGee, Daly, & Jacobs, 1992). Benefits of incidental teaching include the development of skills that are useful and used in children's daily lives. An important advantage of incidental teaching is that parents may be prepared to blend intensive intervention into their naturally-occurring home routines.

However, family supports must go beyond preparation of parents for incidental teaching. We propose that family supports may be the most effective when conceptualized from an incidental teaching perspective. Thus, parents may be most responsive when they are given a broad array of options for preparation to help their child reach his or her potential. When parents can determine the scheduling, setting, and focus of their family program, they can design an individualized program that is tailored to their unique family needs.

Recent developments in early intervention for children with autism are yielding dramatically positive outcomes (Lovaas, 1987; Strain, 1987).

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Moreover, it has been well-documented that parents can play a crucial role as intervention agents for their children with autism (McClannahan, Krantz, & McGee, 1982; Schreibman & Britten, 1984). With lifelong community integration becoming a realistic goal for children with autism, their parents can ensure that intensive intervention begins at an early age.

Concurrent with treatment advances, a nationwide parent advocacy movement has radically altered conceptualizations of supports needed by parents of children with disabilities. Federal legislation such as the Education of the Handicapped Act Amendments of 1986 (P.L. 99–457), now entitled the Individuals with Disabilities Education Act, has formalized the role of parents as meaningful participants in planning their child's treatment. This new opportunity for impact is best realized when parents are informed. In sum, true parent empowerment becomes possible when parents are prepared with knowledge, skills, and the confidence that comes from having knowledge and skills (Ziegler, 1990). An incidental teaching approach is grounded in the assumption that parents will be the most effective in providing and advocating for children's treatments that are compatible with their self-identified needs (Dunst, Leet, & Trivette, 1988).

There are two primary goals of the Incidental Teaching Family Program, originally funded in 1990–91 by the U.S. Department of Education's National Institute on Disability and Rehabilitation Research. First, effective parent preparation is viewed as crucial in pushing back the age at which intensive intervention for children with autism may begin, recognizing that age of intervention may be a principal determinant of positive outcomes for these children. An equally important goal is to expedite the earliest possible empowerment preparation for parents of children with autism because of the importance of parental

decisions while their children are young.

Description of the Incidental Teaching Family Program

Parents choose from a range of options to develop a program that will best prepare them to teach and advocate for their child. Throughout, there is an emphasis on blending intervention naturally into family life, and on promoting children's inclusion in the community. Format options include: (a) an intensive (weekly) individualized program; (b) ongoing (monthly) consultation; and, (c) a parent information seminar.

Intensive Individualized Programs

Parents meet weekly with a trained Family Liaison at their home, in a clinic (well-stocked with toys and an observation booth), or at their child's preschool. Individualized programs begin with parents' selection of topics from a menu of 47 modules. Each module is accompanied by written materials, which have been edited by parents to be "parent-friendly," that is, free of jargon. Where applicable, reference materials and videotaped vignettes are included in the modules. The modules are grouped into five categories: Incidental Teaching, Advocacy, General Information, Family Issues, and Other Instructional Packages.

Incidental teaching. These modules are designed to enable parents to teach language and social skills without disrupting their daily home routines. Parents learn how to identify and use "teachable moments" that occur in the context of ordinary home activities. Examples of the daily routines that parents have chosen to use for teaching include: Mealtimes, Bathtime, Outside Play, Dressing, Chores, Car Trips, and Play with Neighborhood Children.

Advocacy. The advocacy modules provide parents with the knowledge needed to make informed decisions regarding their child. Included on the menu is information on: Integration, Federal and State Laws, Professional Jargon, Best Practices, Positive Negotiations with Systems, and Evaluation of Future Classrooms.

Menu of Family Options

Incidental Teaching Modules
- Introduction to Incidental Teaching
- Incidental Teaching of Language (9 home activities)
- Incidental Teaching of Social Skills (8 home activities)

Advocacy Modules
- Integration
- Knowing the Laws
- Jargon and Methods Used by Professionals
- Services Available and State of the Art Technology

General Information Modules
- Autism
- Typical Child Development
- Securing Resources
- Balancing Parenting and Personal Time

Family Issues Modules
- Grandparents
- Siblings
- Resources within the Family
- Special Requests

Other Instructional Packages
- Independent Playskills (2 home activities)
- Engagement: Keeping Your Child Busy at Home
- Toileting Issues
- Dressing and Self Care
- Meal Time Issues
- Bedtime Issues
- Routines
- Good Behavior in Public
- Behavior Management

General information. Parents need to develop a solid understanding of their child's disability, and many request assistance in improving the quality of their family life. Modules are available in areas such as Autism, Balancing Personal and Parenting Time (Hall, 1987), and Sibling Issues. Grandparents are often interested in obtaining more information on their grandchild's disability, and they and other family members can be instrumental in supporting parents' intervention efforts. For example, grandparents have learned to do incidental teaching of "cute" conversational skills, siblings have been prepared as peer tutors during reciprocal play activities, and aunts have provided invaluable assistance with toilet training.

Other instructional packages. These modules, based on procedures developed and demonstrated effective in the literature, offer parents help in promoting their child's inclusion in the community. Popular options include Home Schedules (MacDuff, Krantz, & McClannahan, 1992), Remote Reporting (Krantz, Zalenski, Hall, Fenske, & McClannahan, 1981), and Managing Behavior on Shopping Trips (Clark, Greene, Macrae, McNees, Davis, & Risley, 1977). Special requests are also accommodated in areas such as training parents as trainers of respite workers, therapeutic nannies, or Sunday School teachers.

Ongoing Consultation

Parents may opt for monthly contacts, either in lieu of or as a followup to the intensive program. In followup, parents are able to design and implement new child treatments, but they sometimes desire professional input and reassurance that their plans are sound. The topics of consultation contacts are usually determined by families at the time of the meeting. When parents are in the process of making placement decisions for their child, they may use consultation to help screen and evaluate potential classrooms, or to select and train a classroom aide.

Parent Information Seminars

As in the other program formats, the topics and scheduling of group meetings are selected by participating parents. Seminars consist of didactic presentations, with accompanying written handouts, and videotaped examples or films. Additionally, group discussion permits parents to share successful experiences with one another. When applicable, guest speakers are invited to provide special expertise (for example, an attorney may present on Disability Law, or a speech and language specialist may address more typical language development).

Evaluation

Participating Families

The families of 13 preschool age children with diagnosed autism spectrum disorders participated in evaluation of the initial program. One family with triplets with autism was allotted the option of program time for three families. Half of the children were simultaneously enrolled in a university-based integrated preschool program (McGee, et al., 1992). Others were concurrently receiving minimal services from their local school districts (i.e., their participation occurred during transitions across programs, and during summer months). The children, including 11 boys and 2 girls, presented a wide range of levels of functioning. Their families represented low to upper-middle socioeconomic households.

Parent Participation

The project initially offered up to four hours of individualized meeting time per week, over a period of up to five months. Measured in time of direct contact with Family Program staff, parent participation averaged 38 hours per family (with a range of 12 to 108 hours across children). Most families reported investing additional intervention time with their child, many on a regular daily basis.

Parents chose to receive two-thirds of their staff contact time in home visits; remaining contacts were distributed across group meetings and school- or clinic-based sessions. It may be noted that Family Program staff spent approximately the same amount of time available for home visits in travel to and from homes.

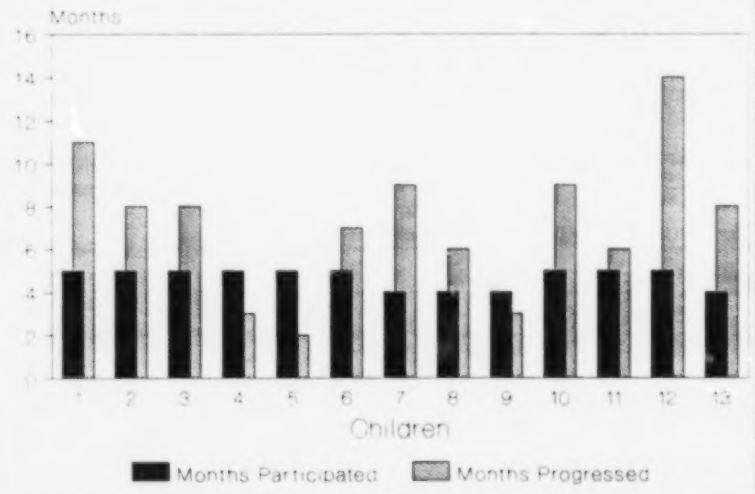
As may be expected in a parent-choice program, levels of reported parental satisfaction were high. One area of feedback, however, was that most parents (including those with the highest levels of participation) would have preferred even more hours per week over a more extended period of time.

Child Outcomes

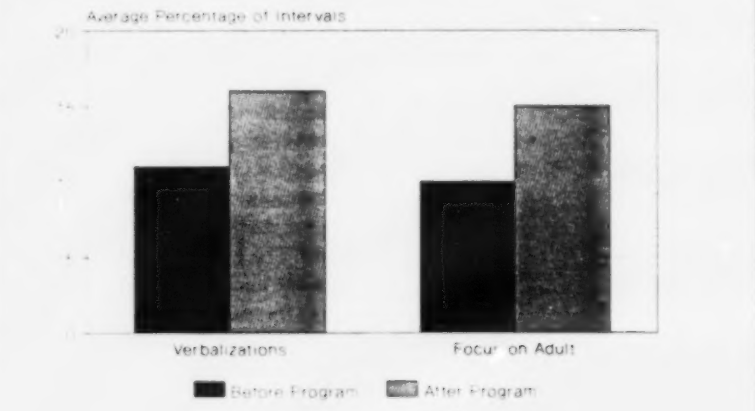
The Vineland Adaptive Behavior Scales were administered (with parents as respondents) at the beginning and end of participation in the Intensive Family Program. The children showed an average of 1.5 months' growth for every month of participation. As shown in Figure 1, 10 of the 13 children showed progress beyond what would normally be expected (progressing from 6 to 14 months in a 5-month period). The families of two of the three children who made more limited progress had chosen to participate for limited hours, and they completed fewer modules.

For 12 of the children, videotaped observations were also obtained in the home at the beginning and end of the Intensive Family Program. In each assessment, a total of 50 minutes of observations were comprised of a snack or family meal, a self-care routine, play with parents (and siblings, if applicable), and independent play. Videotapes were coded using conservative measures of language and social behaviors. As shown in Figure 2, the children of parents who had selected preparation in language instruction modules showed an average increase in the distribution of their verbalizations from 11 percent to 16 percent across home activities. Only one family did not choose language modules, and although this child showed language gains at school, he showed decreases in language use at home. Similarly, children in the six families who selected social modules increased their focus on (watching or interacting with) their parents from an average of 10 percent to 15 percent of time in home activities. Children in the six families who did not select social modules showed no change in their focus on adults across the program period. Changes in levels of engagement were highly variable across children, suggesting the need for curriculum adjustments in this area.

Children's Adaptive Behavior Gains Across Period of Family Participation.



Home Videotaped Assessments of Children Whose Parents Selected Language or Social Interventions.



Perhaps the best measure of advocacy preparation is evidenced by children's placements. Within six months of program participation, 12 of the 13 children were enrolled in fully integrated classrooms.

Dissemination

A community conference was held to provide information on autism and the rights and needs of parents of children with autism. The target audience included early intervention providers, parents, kindergarten teachers, and specialized professionals; conference enrollment was full with 125 attendees. The agenda included nationally-recognized guest speakers, a panel of community service providers to discuss local success with integration, and presentations on the Incidental Teaching Family Program by project staff.

Replication

To date, an additional 15 families have participated in the Intensive Family Program, and many more have benefited from the Parent Information Seminar and written program modules. Project staff relocated from the University of Massachusetts at Amherst to the Emory Autism Resource Center at Emory University School of Medicine (Atlanta), and the new program is replicating well.

However, demand for services is high in a major metropolitan area, and program adjustments have been made to attempt accommodation of a lengthy waiting list. Currently, there is less flexibility in scheduling and reduced opportunity for home visits (which are now monthly, supplemented with weekly clinic visits). The Parent Information Seminar has increased from one to two meetings per month, and these meetings have been opened to the general community. Efforts are continuing to determine the most effective balance of program quality and community needs.

Conclusions and Future Directions

An incidental teaching approach to family supports enables parents to maximize their child's overall progress. By incorporating incidental teaching into home routines, parents can provide an intensive part of their child's treatment and maintain normal family living. By becoming informed advocates for their children, parents can contribute proactively to their children's futures.

In sum, children benefit most when there are opportunities for their parents to initiate the supports they want. Thus, evaluation data demonstrated that children made greater progress in the areas their parents chose. Parents are capable of making intelligent and useful choices based on their goals for their children and families.

Importantly, an Incidental Teaching Family Program provides for parents who have less time and resources to become meaningfully involved in their child's treatment. A central position of this approach is that parental decisions are always respected. However, parents are also informed that more treatment hours at home generally translates to more child progress. When professionals inform and parents make choices, the collaboration yields a productive and flexible family support package.

A limitation of this program is that it is labor-intensive on the part of professional staff. There is a need for continued evaluation of adjustments that will increase efficiency without sacrificing quality. Additionally, there is a need to develop professional training sequences so that larger numbers of families may benefit.

Future directions are also aimed at reaching families when their children with autism are as young as possible. Work has recently begun on adaptations of the program to meet the needs of families of toddlers with autism. By preparing families to determine how they can best help their young children, they will be provided with opportunities to help at the time of greatest impact.

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Serving the Needs of Children with AIDS and Their Families

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"When I found out my baby was HIV-positive, and that it was me who gave it to her, it felt like the whole world was crashing down on me. I was so scared and ashamed to tell anyone."

"I didn't know what people would think or how they would act. I decided to keep my baby at home. . . I wanted to protect her."

"When my family found out, they wouldn't come to visit or even talk to me."

Comments of mothers of HIV-infected children

The National Commission on AIDS, in its first report to the President, stated: "As a society, we claim to protect and cherish our children but, in fact, we have placed women and children squarely in front of an onrushing HIV epidemic."

Unfortunately, those words have proven to be all too true. Women and children are now the fastest growing segments of the HIV population. Every day, six children are born HIV infected in this country. That is 42 children a

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week—enough to fill six infant classrooms. Since all of these children are born to families in which, at minimum, the mother is infected and, in many instances the father and another child as well, AIDS, in the truest sense, is a family disease.

This fact separates pediatric AIDS from all other childhood diseases and has enormous implications for the health and social service systems. Never before have we been confronted with serving an entire family that is terminal and among the most marginal and disenfranchised members of our society. To understand the extent of their disenfranchisement, one only needs to examine the profile of HIV-infected children and their families in America:

- The majority are poor and live in urban settings. These are communities characterized by high levels of poverty, high infant mortality rates, substandard housing, limited access to transportation, and a shortage of adequate health, developmental, and social services.
- The majority of mothers infected with HIV have either been a partner of a substance abuser or have a history of substance abuse themselves. This not only compromises their health and the health of the child but also makes women reluctant to seek medical and drug treatment for fear of losing their children to child and protective services.
- More than 80 percent are from minority backgrounds and have been subject to racism and discrimination.
- Most of the mothers are single parents, with limited job skills, education, and financial resources.
- And finally, all of these families suffer from the negative stigma that is attached to being HIV infected.

As a society, we have yet to address effectively the issues of poverty, substance abuse, and racism. It is no wonder that, when all these issues exist within a family with AIDS, the result is an immobilized social service system and a family that is woefully underserved or inappropriately served.

Even when services are directed to children and families affected by AIDS, they are often misdirected. For example, the main focus for funding for the treatment and care of children with HIV/AIDS has been to hospital-based programs for extremely sick infants, and to residential homes for abandoned "AIDS orphans."

The impetus for this funding focus is based on two widely held misconceptions about children with HIV infection, both of which have been fostered by widespread and compelling media stories.

First, there is the misconception that the majority of children with HIV infection are very ill and have a short life span. The fact is, more than half of these children will live well into their school age years. In a recent study that followed 1,000 HIV-infected children, the median age was nine years.

The second misconception is that most of the children with HIV are abandoned by their families and left to waste away in hospitals. The fact is that the majority of children with HIV infection live at home and are cared for by their families or extended families. True, some have been placed in foster care because their family members were not physically or emotionally able to care for them, but many have been placed because their families had limited financial and social resources and there were no community-based child and family AIDS service programs available to support them and to help them care for the child at home.

What Do Families Need?

Given these realities and the complex profile of children and families living with HIV disease, the question then becomes: How do we mobilize the health and social service systems to help children and families affected by HIV and/or AIDS?

The first step in answering the question is to identify those services that children and families need to enable them to sustain their health and stability so that they can remain together as a family.

The service needs most often identified by the families who have sought help from the Foundation for Children With AIDS during the past seven years include:

- coordination of medical care for both parents and children;
- help in finding housing, fuel, clothing, and other survival basics;
- a therapeutic day and respite program for the children, which not only provides the parents, many of whom are symptomatic, with a break from the daily stress of child care but also provides the child with opportunities to learn and play with other children and have normal childhood experiences;
- referral for drug treatment and ongoing recovery support (80 percent of the parents in our program have a history of substance abuse);
- home and center based early childhood intervention services to address the child's developmental needs (90 percent of HIV-infected children have some form of developmental delay);
- nutrition counseling and education;
- parent education and peer group support;
- therapeutic services, such as individual, marital, death and bereavement counseling;
- home health and homemaker support, including a home visiting nurse, a home health aide, or a homemaker to help with chores;
- hospice—at home as well as at a family residential program for both the infected parent and the child;

- specialized foster care for the children when the biological family is unable to care for them;
- legal assistance with wills, adoption, guardianship, and other custody issues for both infected and healthy children in the event that family members become incapacitated or the children become orphaned;
- advocacy and assistance in negotiating the health and social service system is one of the most important services because it is through the families' ability to identify and access services that they will be able to meet their needs.

What Do Families Want?

In addition to examining what these families need, it is even more important for service providers to know what families want in the way of care, assistance, and support. In 1988, a national meeting for HIV affected families from across the country was sponsored by the Maternal Child Health Bureau of the U.S. Department of Public Health in Washington, D.C., in cooperation with the Association for the Care of Children's Health. The purpose of the meeting was for government officials and professionals to hear directly from families what services they were, or were not, receiving and which of these services they found to be the most helpful in coping with their disease. The parents reported that:

- Services were the most helpful when they were both comprehensive and coordinated. The availability of support from a single identified person was mentioned by several of the families (both foster and birth parents) as the one factor, more than any other, that enabled them to keep their children with HIV infection at home.
- Services that were the least helpful were those that were provided in a piecemeal fashion and required the families to be responsible for locating and coordinating those services. Such lack of coordinated services was the most frequently voiced complaint by the families. If families had to find and coordinate service from various providers without assistance from someone who "knew the system," the families reported that they felt angry, stressed, and overwhelmed.
- Families who were in support groups with other families of children with HIV infection felt this activity to be a primary support. Through participation in such groups, these families were able to develop supportive relationships with other families.
- Crucial to their ability to cope was the need to remain hopeful. Although the families were fully aware of the prognosis for their children and themselves, they all expressed a need to feel hopeful and to know that a feeling of hope was also shared by the health care, education, and social service personnel serving them.
- High on their list was their desire for understanding from others. They reported that public information about HIV infection and the attendant fear had devastating repercussions for them and their children and had resulted in job loss, ostracism in the community, and being treated with fear and suspicion by service providers.

Programming That Meets Families' Needs

In the past seven years in our work with children and families affected by HIV and/or AIDS, our goal has been to support families and to help them sustain their health and stability so that they can continue to care for their children at home.

In response to the needs families have expressed for services, we have developed a model program, **Project STAR**, that is confidential and safe for families, addresses their psychosocial, financial, and health needs, and supports them to experience the best quality of life for as long as possible.

Project STAR is a home and center based child and family care program serving 46 children and their 150 family members in the Greater Boston area. In 1992, **STAR** was cited by the Surgeon General as an exemplary program, a program to be replicated in communities throughout the nation.

As we learned from our experience with **STAR**, to be effective, a program for children with HIV infection and their families should have the following characteristics: it should be family centered, community based, comprehensive, both home and center based, and it should coordinate services across those agencies that are serving the family.

Family Centered and Community Based Services

By family centered, we mean that service providers should recognize the family as the child's primary care giver and empower that family to direct the care provided to the child and to family members. It is important to recognize that care of the child in the home by the family is the most cost effective service option.

Compare the costs: caring for a child in foster care is approximately $25,000 per year; for residential care it is $85,000 per year; caring for that child in a hospital is approximately $287,000 a year. By providing family centered and community based care, we keep the child at home longer and address the needs of the entire family, preventing or delaying the child's placement in foster care, group care, or extended hospitalization. The cost to provide the comprehensive array of services available to families at **Project STAR** is approximately $12,000 per year.

Comprehensive Services

Medical management of HIV disease is only one aspect in the proper and effective care of the child with

HIV and/or AIDS. Families living in high risk communities also face tremendous stress due to social and economic factors; stresses that are further compounded by the psychological impact of the disease.

For the children at **Project STAR,** there are a variety of stressors. All of the children live in a home where the mothers are single parents and heads of household. Two of the families we serve share their home with other families just to help pay the rent. Many of the mothers are struggling with denial of their or their child's illness, and feelings of guilt and remorse, and loneliness and isolation because of their condition.

Additionally, all of the families we serve deal with the daily stress of witnessing either their own or their child's debilitating disease. Some of the medical problems the children experience are seizures, respiratory problems, asthma, sinusitis, rashes, thrush, infectious pneumonia, tuberculosis, bacterial infections, diarrhea, speech delay, chronic colds and low grade fevers, growth delays, and cognitive and motor regressions.

In combination, these stressors place the HIV-infected family in a state of constant turmoil, ongoing crises, with intermittent periods of despair. Programs serving these families must recognize the complex nature of their lives and be organized to respond to their specific needs. They must provide a range of services that address the medical, developmental, financial, and psychosocial needs of the children and their families. This comprehensive approach improves the families' ability to cope with the disease and to manage any problems and crises that arise.

In addition, programs must address the service needs of the entire family, which includes the child, the mother, the infected and healthy siblings, as well as any other family members or significant others.

Home and Center Based Services

In providing comprehensive care to families, both home and center based services are needed. By providing therapeutic intervention in a center, the developmental needs of the children and the psychosocial needs of their care givers can be simultaneously addressed. Quality therapeutic intervention by a clinical staff, such as occupational, speech, and physical therapists, and child development specialists, is an important need shared by all families.

Day care also offers parents the time to go to their medical and drug treatment appointments, to spend time with their other children, and to attend to routine household demands. Almost all of our families come to us needing day respite services. Some of our mothers, especially during bouts of illness, are in need of day and overnight respite care for their children.

Because of the fluctuating condition of family members infected with HIV, service providers must be prepared to deliver their services in the home, or in some cases, in the hospital or at friends' or family members' homes, when the mother and child become ill. Even in those cases where the child and the family are healthy, it is important for services providers to go into the families' homes. In doing so, service providers acquire a realistic understanding of where and how families live, and are better able to comprehend and address the stressors family members face in their day-to-day lives. Home based service also offers the parent some exclusive one-on-one time with service providers.

Coordinated Services Across Agencies

Because it is not possible for one agency or program to provide all the services required by families with HIV, referral to other agencies and coordination of these services is an essential component of **Project STAR.** Most of the families we see are involved with at least five outside agencies and care providers. It is not uncommon for each of these agencies to have different policies, procedures, and requirements, and their own schedule of appointments for the families to meet.

For someone who is able bodied, juggling the demands and expectations of these various agencies can be trying. For a single parent who is ill and caring for an ill child, the process can be overwhelming. It is important that the services be offered in a continuum of support that enables the family to move from one service option to another. The structure we have used for achieving this coordination across agencies and professionals is the transagency/transdisciplinary model, which organizes a group of providers into an integrated network that can be easily accessed by the family. Also, it is vital that the family have access to a single professional within the network who serves as the advocate for the family and assists them in accessing all necessary services.

Community Based Services

Programs and services need to be located within the community where the families live. They must also be accessible both physically and culturally, and reflect a sensitivity to the racial, ethnic, cultural, and socioeconomic backgrounds found therein.

It is also helpful for these programs to be housed in a building that is shared cooperatively with other programs for women and children. For some families, a program in a facility identified as exclusively serving children and families with HIV/AIDS would be too conspicuous and might prevent them from utilizing the program.

It is essential that the staff in these programs be empathic and feel comfortable about working with HIV-infected children and their families who may have a history of substance

abuse. Staff must also have the skills and experience to work with high risk families who have complex and multiple service needs.

The Need for Safety and Confidentiality

The negative stigma attached to AIDS very often frightens and isolates mothers of children with HIV infection. As a result, they are often reluctant to seek support and treatment for fear of the negative consequences they will encounter once they disclose their status. This is especially true of mothers who are ill themselves and have a history of drug use. Many women find out they have HIV at the same time they learn that their child is infected. This "double shock" often incapacitates them.

It is at this crucial time in the lives of children and their families that parents have need for a program in which they can orient themselves to life with the disease, stabilize their emotional states, access developmental services for the child, receive counseling, and gain support from other families who are struggling with HIV/AIDS. Eventually, with this kind of support, families will become more comfortable about disclosing their HIV status and can seek support from other programs.

For many in the field, these specialized services stand in stark contrast to the prevailing orientation toward mainstreaming for all children with special needs. In the face of this concern, the ultimate question becomes: Without such specialized programs, which are designed and committed to providing comprehensive and intensive services to children and families with HIV infection, could these families obtain services and care through most mainstream programs?

At the present, we believe the answer is no. Traditional programs—Head Start, day care, early intervention programs, preschool, and others—were neither designed nor staffed to deal with families with AIDS, nor to address the issues of substance abuse or terminal illness.

In addition, there is evidence to suggest that many of the professionals in these programs are reluctant and, in some cases, unwilling to work with children and families who are HIV infected. In the March/April issue of "Children With AIDS" newsletter, there was an article citing three recently released studies that surveyed the attitudes of special educators, elementary school teachers, and day care providers regarding their feelings about having HIV-infected children in their classrooms, and their right to know which children in their classrooms were infected. The studies showed that a majority of those surveyed had strong feelings about the right to know about HIV-infected children in classrooms; and, if given a choice, wouldn't want to teach them.

As a veteran in the fields of child development and special education, I've been a staunch advocate for, and defender of, the concept of mainstreaming for all children with special needs.

However, for many of the families living with HIV, especially those in which an infected caregiver has a newly diagnosed child, many mainstream programs may not be available. In fact, many families might choose to have no services at all rather than having their HIV status known in the community.

If our goal is to keep families together, to help them physically and emotionally to live the best quality of life, then programs such as **Project STAR** have a valid place in the service continuum. We emphasize that the role of the segregated program is transitional in nature. These programs should be designed to serve as a haven for parents and children, a place where they can find the support and confidence to move into the mainstream when their children are of preschool or school age.

If these programs do not exist, many families caught in the crisis of their AIDS diagnosis will fail to seek services and support. Many families will be overwhelmed and place their children in foster or residential care at substantially greater costs to society. Though we must support intensive professional education and training for staff in mainstream programs serving HIV-infected children, we must not ignore the importance of transitional programs for those more vulnerable children and families who are in desperate need of quality comprehensive care. ♦

Serving Students with Emotional and Behavoral Disorders through a Comprehensive Community-Based Approach

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Recent reports on the low levels of success in educational programs for students with emotional and behavioral disorders (EBD), the limited availability of related services, and a lack of collaborative, interagency practices indicate an urgent need to reconsider how school and community services are provided to these students and their families. To serve this population effectively, school districts and communities need to develop and implement comprehensive, community-based systems of services and support. Addressed in this paper are the

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issues and strategies involved in developing these integrated services. The purpose of this paper is to provide educators and community stakeholders with information and resources to help them begin programs in local communities. First, the need to develop comprehensive, community-based programs is established through a review of data regarding the prevalence of mental health problems among children and youth and the financial costs of traditional methods of serving these students. Then, the issues that are essential to developing a comprehensive, community-based approach to serving students with emotional and behavioral disorders are presented.

Need for Comprehensive Community-Based Services

Emotional or behavior disorders (EBD) present families and communities with significant social and financial challenges. Recent government reports and other professional literature indicate how our social institutions are affected by problems related to these youngsters and families. Although such reports typically understate the full nature of the problem, they nonetheless suggest the enormous human and financial costs of providing traditional, restrictive services to this population. They also strongly suggest the need for providers of care to these youngsters and families to examine the manner in which services are provided.

Prevalence of Behavior/Emotional Disorders

A consistent trend in the prevalence of children's mental health problems has emerged over the past 20 years. The Office of Technology Assessment (1986) reviewed existing research and concluded that 11.8 percent or 7.5 million children and adolescents were in need of mental health services. In education, the number of students receiving services for EBD in the public schools has risen over the years. In 1978, the prevalence of students identified as EBD was 0.5 percent; more recent figures estimate the prevalence of students identified as EBD at approximately 1 percent.

Estimates of Restrictive Educational Placements

In 1990, students with EBD were educated in self-contained special classes (35.8 percent), separate schools (13.4 percent), residential facilities (3.8 percent), and homebound/hospital placements (2.9 percent) at rates much higher than students with other disabilities. For example, although students with EBD comprise only 9 percent of all students in special education, they represent more than 50 percent of all students served in residential facilities (U.S. Department of Education, 1991).

Estimates of Out-of-Home Placements

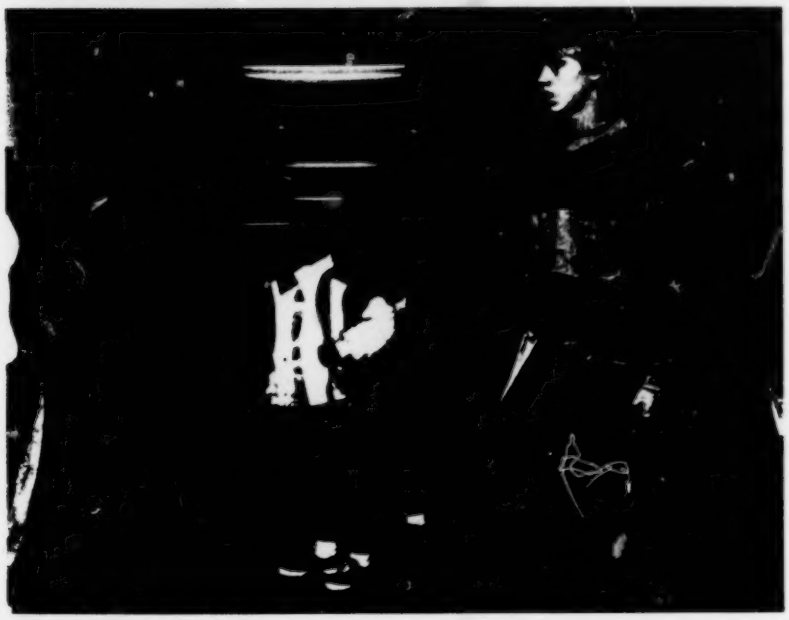
In 1989, nearly one-half million children were estimated to be in out-of-home placements (Select Committee on Children, Youth, and Families, 1989). Out-of-home placements typically used to serve students with EBD include foster care, hospital, and residential facilities, and correctional settings. Foster care, the most widely used out-of-home placement, served more than 340,000 children in 1988 (Tuma, 1989). More than one-half of the children and youth in long-term foster care are in need of mental health services, but less than 15 percent receive adequate services (Tuma, 1989). Each year a significant number of children and youth are also admitted to mental health facilities. In 1986, approximately 55,000 children were in residential mental health care and recent evidence suggests that many of these individuals were being placed in psychiatric hospitals unnecessarily (Behar, 1990). In 1987, more than 91,000 adolescents were held in public and private juvenile correctional facilities, a 40 percent increase from the decade earlier (Select Committee on Children, Youth, and Family, 1989).

Estimates of Financial Costs

The manner in which education, mental health, and other agencies currently serve children and youth with EBD results in extensive financial costs. In 1985, mental health services for children 14 and under were estimated at 1.5 billion (Institute of Medicine, 1989). One billion dollars are presently being spent each year for the hospitalization and residential treatment of children (Yelton, 1991). In 1986, public juvenile correction facilities cost state and local governments nearly 1.5 billion dollars to operate. Perhaps one of the most obvious indicators of the need to provide community-based programs is the cost of out-of-community care. A recent survey of 37 states reported that more than 4,000 youth were placed out of their home state at a cost of $204,000,000 or an average of over $50,000 per youth, per year (VanDenBerg, 1989).

Effectiveness of Out-of-Community Care

Out-of-community placements present a number of service related problems (VanDenBerg, 1989). First, the local community's ability to monitor student progress is severely restricted by its lack of proximity to the placement sites. Second, student progress reports may not always be objective given the substantial financial contingencies at stake (e.g., $200 per day) for those providing the services. Third, generalization and maintenance of treatment gains to the home and community usually are not planned, minimizing the likelihood that these gains will persist upon discharge. Fourth, restrictive, out-of-community placements limit family participation in the development and provision of services. This contradicts the current views of many mental health and social service professionals who believe the most important social institution in a child's life is the family (Friesen & Koroloff, 1990).



Summary

The aforementioned data on children and youth with EBD suggest that a significant number of them are experiencing mental health, social, and educational problems. These problems are very costly to the child, the family, and the community. Although many schools and communities elect to serve these children and youth in restrictive, out-of-community settings, research and common sense suggest that this is an ineffective and costly intervention.

Comprehensive Community-Based Services

In this section, issues considered critical to developing and implementing a comprehensive, community-based service model for children with EBD and their families are presented. This model is a "best practices" approach to providing comprehensive, community-based services to children, youth, and families. Recently, several initiatives to meet the multiple and changing needs of this population through integrated services have been launched on the national, state, and local level (Beachler, 1990; Behar, 1985; Burchard, Schaeffer, Harrington, Rogers, Helkowitz, & Tighe, 1991; Jordan & Hernandez, 1990; Nelson & Pearson, 1991; Stroul, 1985; VanDenBerg, 1989). Based on these initiatives' innovative features, we believe that planners must achieve agreement on the following issues relative to developing a comprehensive, community-based model of services. These issues include *developing a system of care, target population definition, principles of care, comprehensive needs assessment, individualized care,* and *evaluation.*

A System of Care

A complete, community-based *system of care* refers to "a comprehensive spectrum of mental health and other necessary services that are organized into a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents" (Stroul & Friedman, 1986, p. iv). The development of a system of care, therefore, requires collaboration and cooperation among professionals from various child care agencies. *Interagency collaboration* has been a primary goal of previous mental health initiatives to serve children and youth with EBD. A comprehensive interagency system of care model should feature the following seven function-specific sources of service: mental health services, social services, educational services, health services, vocational services, recreational services, and operational services (Stroul & Friedman, 1986).

Successful interagency collaboration involves a specifically delineated arrangement among the primary child care agencies. This arrangement speaks to vital issues such as agency responsibilities, service financing, joint system planning, and collaborative programming (Duchnowski & Friedman, 1990). The details of such arrangements should be carefully explicated in written joint agreements that are mutually developed and officially approved by the executive directors of all pertinent agencies. Written joint agreements provide permanent guidelines that establish accountability and ensure continuity of service regardless of staff turnover.

Definition

Agreement on a *definition* of the specific target population to be served via interagency collaboration is another essential issue affecting the development of an effective community-based system of care. A population definition assists cooperating agencies in determining service eligibility criteria, service provision responsibility, and service payment responsibility. Developing an operational definition of the targeted population has been an initial activity in previous interagency initiatives (e.g., Jordan & Hernandez, 1990; Magrab, Young, & Waddell, 1985). Because the needs of local communities will vary, the definitions of target populations will differ from community to community. For example, in Ventura County, California, the target population of children and youth who have first priority for services through the interagency system of care is defined as those with a DSM III-R diagnosis, a severe functional impairment in the home, school, and/or community, and a risk of or actual separation from the family (Jordan & Hernandez, 1990).

Principles of Care

A third essential issue is the extent to which policy makers reach agreement on the *"principles of care"* that will establish the direction and purpose for the community-based program. Policy makers should consider important issues such as goals, accessibility, family involvement, and the comprehensiveness, individualization, coordination, integration, and evaluation of services in the desired system. The agreed upon principles provide the context or climate in which services will be delivered. Community-based programs that have been successful have developed an agreed upon set of principles (Jordan & Hernandez, 1990; Stroul & Friedman, 1986).

Needs Assessment

To develop a comprehensive, community-based system of care, it is necessary to examine the complex and diverse needs of those targeted for service and the equally multifaceted needs and resources of service providers and social agencies. The overriding objective of a *needs assessment* is to obtain sufficient information for drawing accurate conclusions about the current system of care without becoming involved in a complex, expensive process which, in itself, becomes a barrier to system development.

In a model program of services, a three-phase needs assessment should be implemented. First, an archival review of children and family previously served should be conducted (Burchard et al., 1991). An archival analysis involves a systematic, retrospective review of select individuals' case records. Second, a survey of direct service providers from the primary child care agencies should be conducted (Arizona Department of Health, 1991; Friedman, 1988). This information provides data on the current quantity and quality of the service currently being provided. Third, an *interview* should be conducted with a representative number of children, parents, teachers, social workers, mental health workers, probation officers, policy makers, and others who have or will provide services (Arizona Department of Health, 1991; Burchard et al., 1991). Individual interviews should consist of carefully chosen open-ended questions about the quality and quantity of the services provided, barriers to services, and strategies for improving these services. Using these data, representatives from the primary child care agencies can then develop an action plan for improving the existing system of care.

Individualized Care

Agencies need to totally commit to serving the child and his or her family on an individualized care basis. The principle of *individualized care* is based on the development and evaluation of programs such as Kaleidoscope (Burchard & Clarke, 1990), the Alaska Youth Initiative (VanDenBerg, 1989), and Project Wraparound (Burchard & Clarke, 1990). In individualized care, the child's specific needs rather than availability of existing services determine treatment structure (Burchard & Clarke, 1990; Burns & Friedman, 1990). Having the latitude to allocate creatively and adjust resources is essential, however, parents, case managers, and program evaluators must also be able to ensure that all services called for in the treatment plan are actually provided as planned. The principles of individualized care central to a model program of services are *unconditional care, intensive case management, family involvement,* and *cultural competence*.

Providing *unconditional care* means that no child will be denied services and that each child will receive services in as normal a community setting as possible until he or she no longer requires services (Burchard & Clarke, 1990). That is, there are no predetermined criteria for emotional or behavior problems beyond which termination will occur. In *intensive case management*, a single case manager is assigned to work with a child and a family for as long as the services are needed. Case managers provide for the development of an overall treatment plan, broker services essential to meet treatment goals, and monitor treatment outcomes, thereby ensuring that intervention strategies are adopted to changing child and family needs. The practice of *family involvement* is founded on the premise that children are best served by the family unit. Family involvement means empowering families (e.g., family advocacy and parent rights) and providing direct services in the home setting (e.g., parent training, respite care, or crisis management). Model programs must also provide *culturally competent services*. Cultural competence underscores the importance of culture, the assessment of cross-cultural relations, vigilance regarding the dynamics of cultural differences, expansion of cultural knowledge, and modifications to meet cultural needs (Cross, Bazron, Dennis, & Isaccs, 1989).

Commitment to Evaluation

If provided services and desired outcomes are to be satisfactory, thorough evaluation procedures are essential. Information obtained through these procedures allows administrators and service providers to direct system development and growth, document which children and youth respond well to community-based programming, and measure the long-term impact of such treatment on the children and families served.

To accomplish these goals, an evaluation plan that provides a blend of quantitative and qualitative data collection instruments should be developed. Evaluation information should focus on child, youth, and family needs, service outcomes, and the process and product of the service delivery system. Areas of evaluation should include child status, family status, interagency collaboration, community-based service provi-

sion, and background information. Also of interest are such outcomes as changes in important target behaviors and the social validity of these changes, cost effectiveness, range of placements, and the levels of collaboration and satisfaction of participating agencies.

Summary

In the 1980s, the mental health needs of the children and youth in our society were dramatically reported in numerous publications. In reaction, federal and state governments, and private foundations promoted initiatives to improve services for children and youth with emotional and behavior disorders. Selected programs at the national, state, and local levels have identified a set of best practices essential to the development of a comprehensive, community-based model of services. Local communities wishing to develop this model of service delivery need to address the issues of developing a system of care, target population definition, principles of care, needs assessment, individualized care, and evaluation. Collectively, these issues will significantly challenge advocates, agency administrators, direct service providers, parents, and children and adolescents. Nonetheless, the strategies to resolve these issues are available to local communities interested in planning, implementing, and evaluating a comprehensive community-based system of care. ❦

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Transition Planning for Individuals Who Are Deaf and Blind: *A Person-Centered Approach*

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Introduction

The world is changing dramatically for persons with severe disabilities. Not only has education become an inalienable right but there is also a growing expectation for each person to participate fully in all aspects of school and community life. We are becoming more sophisticated in our ability to deliver services and organize resources to help more individuals exercise their full citizenship. The initiatives and priorities of the Office of Special Education and Rehabilitative Services (OSERS) represent this trend and commitment.

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Functional curriculum, activity-based lessons, neighborhood school placement, school inclusion, and the transition from school to work are familiar issues associated with best practice for students with severe disabilities. Concomitantly, educational practices and technologies have improved in relation to the unique needs of students who are deaf and blind, especially in areas such as communication, orientation, and mobility skills instruction. Many of these improvements are occurring in settings and schools that are in the process of restructuring. This article will describe the **Transition Occupational Placement for Students (TOPS)** project. TOPS has been implemented in a large, diverse urban community. It represents the collective efforts and contributions of many agencies and individuals. The TOPS consortium was organized by San Diego State University Interwork Institute and the Sweetwater Union High School District. TOPS has attempted to involve students who are deaf and blind as a part of the community's overall effort to better meet the needs of all students. TOPS is a demonstration project struggling with the issues associated with change, attitude, budget, disagreement, and technological advances. At the same time, Sweetwater students who are deaf and blind are now active members of their high schools. They are involved in classes, clubs, and jobs. Many nondisabled peers have developed skills to interact effectively with their new found friends.

TOPS was designed to restructure services provided to students who are deaf and blind. Currently, many experts in the areas of deafness and blindness need to develop new commitments and competence to support this group's full inclusion in school and community. Many with expertise in supporting school and community inclusion need to develop skills in providing and coordinating services often specific to the needs of students who are deaf and blind. Until the gap is reduced in this "specialist-generalist" dilemma, students who are deaf and blind will continue to be underrepresented in many new and exciting school inclusion initiatives. This underrepresentation can be summarized by the following.

- Best practices as it relates to integration, functionality, peer relationships, and transition are often denied to students who are deaf and blind.
- Conversely, when best practice is provided to students who are deaf and blind, specialized considerations such as communication, orientation, and mobility are often neglected. For example, techniques for uses of calendar boxes, name signs and orienting students to a task, are not generally known across educators.
- Services for students who are deaf and blind are based on a heavy reliance on one-to-one staff to student instructional ratio, a ratio which is hard to support in school and virtually impossible to support in adulthood leading to a considerable amount of noninstructional "dead time."
- Parents of students who are deaf and blind, as with other families, range from being very involved to quite uninvolved in their child's education. Very involved parents have often attempted to learn about deafness and blindness and advocacy and are sometimes resentful of the school system. Parents who are generally uninvolved have often not been actively or effectively solicited and supported by the school system.
- There have been few active attempts to secure input and active involvement of siblings and peers beyond peer tutoring programs.
- Few sustained friendships exist between most students who are deaf and blind and nondisabled individuals.
- Limited transition planning has resulted in adults, who are deaf and blind, leaving school and not participating in new supported employment and supported living initiatives.
- Instructional programs and resources should be better organized and developed for issues such as staff competence, scheduling, integration, lesson planning, and data keeping (Kaplan, 1989; Falvey, 1989; Haney, 1988; Perske, 1988).

TOPS was designed to demonstrate services that produce results and that challenge these generalizations. TOPS was designed to ensure that students who are deaf and blind are well represented in efforts to improve and restructure school and community services. Specifically, the project was designed to:

- enhance meaningful integration in a wider range of school and community environments;
- expand the concept of transition from that of school to work to that of school to adult life;
- use person-centered planning strategies to more actively involve parents, other family members, peers, friends, and co-workers;
- better infuse skill instruction into functional activities incorporating systematic instruction, augmentative communication, calendars, technological devices, and other individualized adaptations; and
- establish more effective instruction and support plans that impact on where individuals spend their time, what they spend their time doing, and with whom they spend their time.

TOPS has developed, adopted, and demonstrated many strategies to facilitate inclusion, person-centered planning, and transition. At the same time, strategies were developed to ensure that their experiences included attention toward needs often specific to

Paulo has been a student in his neighborhood high school for the past year. During his first year, Paulo has had several exciting activities occur to support his active participation in both campus and community experiences. Paulo is 18 years old, severely mentally retarded, and has profound hearing and visual losses. He uses object communication throughout his day and walks using either a sighted guide or a sighted guide and a walker.

Paulo came to the secondary district in a wheelchair, unable to walk or tolerate interactions with staff or peers. A year after coming to the secondary district, Paulo was using a walker. At the beginning of his second year of high school, Paulo's teacher coordinated a futures planning meeting for him. During the meeting, the following areas were identified for development: communication (establish name signs for people in his life), mobility (more independent ambulation without the walker), integration (involvement with the wrestling team), community (shopping for groceries), domestic (self-care and dishwashing). By the end of the year in the high school program, Paulo had participated in a physical education class with same-age peers, had two jobs (recycling and cafeteria), joined an extracurricular high school club (Friday Night Live) and participated on the wrestling team.

Paulo's school routine has significantly changed from when he first started at the high school last fall. This year, for the first time, he is engaged in a variety of general education and community activities. Through the facilitation of a student worker (same-age peer), Paulo is in a general education advanced art and reading class. Paulo's main objectives in the advanced art class are to hold and touch the clay, mold it in his hand for a few seconds and socially have opportunities to meet and make new friends. This is already happening in his reading class. Originally, the inclusion teacher established a goal for Paulo to collect the attendance and take it to the office. However, his sixth period reading teacher decided she wanted Paulo to be included as a member of the class and to have the class be as meaningful for him as it is for the other students. She developed, in collaboration with the inclusion resource teacher, a plan to familiarize Paulo with the classroom surroundings so he would know where he was and then encouraged the other class members to feel free to approach and talk to Paulo. Now many of the students in the class have name signs and talk to Paulo every day before or after class. The goal for Paulo, in addition to participating in the class, is communicating with his classmates.

students who are deaf and blind. One of the major challenges has been to break the heavy reliance on the one-to-one student/staff ratio that is so pervasive in this specialization area. Another challenge was to impact the general awareness, attitudes, and expectations that others have regarding these students. TOPS was designed to help coworkers, general education teachers, peers, and others develop competencies in using specialized orientation and mobility, augmentative communication, and other systematic support techniques.

By addressing these specific concerns within the context of total school restructuring, TOPS has affected a change in services and in the service delivery systems. Students who are deaf and blind are spending time in new places, engaging in new activities, and establishing new relationships. In the remainder of this article, demonstration activities and outcomes will be described across three areas: inclusion, person-centered planning, and transition.

Inclusion

When the TOPS project began, the majority of students who had severe disabilities, including those who were deaf and blind, were served at one central school site. Now, students with severe disabilities are physically located on integrated sites with an increased emphasis on providing education at students' home schools. As a result of this conversion, individual schools are beginning to make site-based decisions regarding the best education practices for students with severe disabilities and how that process fits into the total framework for educating all students. **The inclusion of students in all aspects of school life has been a unifying theme of the project.**

Montgomery High School decided that the traditional service delivery model (special day classes) did not adequately meet the educational needs of the students enrolled in the program. An inclusion team comprised of the assistant principal, general educators, special educators, and a project coordinator from San Diego State University's Interwork Institute set its focus on how to organize an inclusion project that would have a zero reject philosophy. Students, including those who are deaf and blind, have had schedules developed according to their individual strengths, weaknesses, and interests. Ten students are taking classes in 12 different subject areas and have 20 different teachers offering an array of courses to students in grades 10–12. Since the beginning of the school year, the inclusion team meetings have been held every two weeks. The main focus of the meetings is student updates, strategies for ongoing staff communication, support, and problem solving. Discussions among team members have elicited valuable information about the changes in student and

teacher behavior, strategies that are effective with the inclusion of students in regular classes, and changes within the learning environment of the classes themselves.

Significant changes have occurred since the inception of the inclusion project. Teachers have made observations about the overall impact that the project is having on all of their students, including the inclusion students:

- Classes as a whole are not as "rowdy."
- Comfort levels between students, teachers, and inclusion students have improved.
- Students evince more compassion and socialize more with inclusion students.
- Inclusion students are communicating more frequently to both teachers and their peers.

Many successes have occurred. However, many challenges and issues will still need to be addressed in future planning meetings. The project team collectively has developed through this experience a dedication to the success of inclusion students—"to making it work."

Person Centered Planning

New initiatives to create a more collaborative outcome-oriented planning process are occurring throughout the country. Processes that invite participation and focus on an individual's strengths and desires for school and community inclusion are being developed. In these processes, new commitments from paid and nonpaid support people are realized, and there is an expectation that roles and responsibilities will be shared. The process is designed to be dynamic and comfortable as opposed to time-limited and procedure-driven. These developing processes have been organized in several formats, by several names, with many creators. These processes come under the general heading of person-centered planning.

Various versions of person-centered planning with adolescents and young adults who are deaf and blind have been developed under this grant. Each person-centered planning team requires a great deal of personal commitment, creativity, and perseverance. The results and outcomes have been exciting. **Person-centered planning has become the central strategy to achieve inclusion in the project. Much of the change in Paulo's program, for example, is the result of person-centered planning efforts.**

Person-centered planning meetings, such as McGill Action Planning (MAP) meetings or Personal Futures Planning meetings, are designed to generate an action plan to include and enhance an individual's participation in activities at school, home, and in the community (Vandercook, York,& Forest, 1989). These planning meetings often facilitate a student's transfer from one class to the next or are frequently planned to help with the Individualized Educational Plan (IEP), the Individualized Transition Plan (ITP), or the Individualized Program Plan (IPP) development. The goal is to focus on the choices, strengths, and needs of the individual through a coordination of services (Mount and Zwernik, 1989).

Depending on the age of the individual and his or her unique circumstances, a person-centered planning team or "circle" will be composed of family members, friends, neighbors, general and special educators, classmates, or co-workers. One group member serves as facilitator and one records comments and ideas. A variety of information is collected from some, or all, of the topical questions below (Vandercook, York, & Forest, 1989; Mount & Zwernik, 1989):

- Who is the focus person?
- What is the focus person's history/background?
- What are the dreams/goals for the focus person?
- What are the concerns or fears?
- What does the focus person now do? (relationships, places, activities, preferences, choices)?
- What are the focus person's strengths, gifts, and abilities?

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Cristina is a young lady, 22 years old, who recently graduated from the school transition program. Cristina is legally blind and hearing impaired and has some mental disabilities. Cristina has lived in several different group homes since the death of her parents. One of her dreams is to get reconnected with family members and move into a more independent living situation.

As a student in the transition program, Cristina was the focus of futures planning meetings where major issues and changes in her school to adult life were addressed. Participants in Cristina's school and personal life came together to meet in a united effort to plan for the future. Cristina wants to move from San Diego to the Richmond area to be near her family. She needs to find programs that provide instruction in independent living skills and supported employment. Cristina would prefer to live in a supported living situation with one roommate. Professionals and family members in both the San Diego and Richmond areas were involved in the meeting (using a speaker phone in both locations). A great deal of networking had taken place prior to the meeting which resulted in staff participation from several agencies in the Richmond area.

In the school transition program, Cristina has had various work situations and experiences. She has received mobility training and has successfully learned to utilize a cane and travel on public transportation from home to the transition program and from home to work. Cristina's support staff developed a job at a local grocery store during her last year of the school transition program. The manager conducted a modified job interview with Cristina. A picture employee manual was developed highlighting the major people, places, job duties, and equipment she would need to know in the store. The timesheet was enlarged and adapted to meet Cristina's needs. This book was shared and cleared with the manager so that he was aware of the accommodations, techniques, and support being provided to Cristina. The manager of the store felt responsible for training his new employee; therefore, Cristina received natural support from her coworkers. Co-workers ate lunch with her, gave her instructions about coupons, demonstrated job tasks, and trained her to bag groceries, giving her the necessary support until she could function independently. Co-workers have become companions and friends of Cristina, they even surprised her with a birthday party. She continues to work in the grocery store 12 hours per week earning $5.75 per hour. Because of Cristina's success in her employment situation, the planning team decided to ascertain the possibility of transferring her to another branch of the grocery store in Richmond—a move of which the store has been supportive.

Cristina continues to work at the grocery store awaiting a placement opportunity in an independent living situation in Richmond. In addition to working, Cristina has joined a support group facilitated by the Services for the Blind Community Center. The Department of Rehabilitation, Regional Center, and the support network continue to monitor Cristina's activities and maintain contact to facilitate Cristina's move.

The future planning meeting accomplished the goal of developing a strong support circle/network to set her goals and dreams more comprehensively and actively into motion.

- What are the focus person's support needs?
- Who will implement the Action Plan to help the focus person reach his or her goals?

Person-centered planning is designed to put the student at the "center" of the process. The goal is to develop a plan with the student, not for the student. Therefore, it is critical to maximize the student's active participation in the process. Many students who are deaf and blind or have other multiple disabilities cannot readily engage in an exchange of traditional questions and answers regarding their overall interests or what they would like to see included as a part of their educational or adult experiences. This makes their active participation in a meeting challenging. TOPS uses a variety of strategies to maximize student participation and input from those who might otherwise be characterized as "nonverbal." Overt behavior usually has communicative intent. Therefore, a student's "affect" provides the planning team a great deal of insight to preferred and non-preferred settings, events, and people. Facial, vocal, and body movements can be observed to indicate likes, dislikes, and choices. A student's behavior over the years across different school, work, and community experiences can be used to infer likes, dislikes, and needs. Certainly a variety of people who interact the most with a student have valuable contributions to make since they have experienced different activities together and have obtained a significant amount of information from the student. Therefore, people who interact with the student on a regular basis must be prepared to share this type of information.

It is important to make the discussion at the meetings as concrete as possible for the student. If familiar people are introduced by learned name signs, team members can gain some insight by observing the student's reaction. If a student has learned to use a calendar box to understand his daily schedule of environments and activities then this becomes a tool that might solicit information and involvement during the

meeting. If a meeting is being held to focus on particular types of subjects, holding the meeting in a subject-related setting familiar to the student may also help encourage involvement. It would not be hard to see when a co-worker comes to a meeting and provides the student with his name sign that the student's excitement means he likes his co-worker and/or his job. It is also a concrete way to help the student realize that the discussion is now concerning work. Using these referents to current everyday school, work, and home life are very helpful ways to actively solicit students involvement and input.

Videotapes have also been incorporated by the TOPS staff at these meetings so people who do not know the student well can see each functioning at his or her best, in familiar settings and activities, with familiar people, and using effective supports. Videotapes, pictures, and written references represent much more accurately the student's competencies and needs than does performance at a meeting. TOPS has placed a great deal of emphasis on adapting this format to develop formalized active support systems based on the individualized needs of the focus person and to begin to connect students with their community, peers, and co-workers.

George is an 8th grader in junior high. Prior to his arrival at Montgomery Junior High, his previous teacher went to great lengths to ensure a solid support system was in place by writing an IEP developed by his parents and teachers, and by meeting with George's new teachers throughout the summer to facilitate his transition.

George has had many new experiences since his arrival at Montgomery. He has learned to ride the city bus independently from home to school (with the initial assistance of the mobility instructor), to change classes, to work with an interpreter, and is struggling to establish his identity just like any other junior high student. During the spring of 1992, three of his teachers decided to plan a MAP meeting to help George prepare for the 8th grade. Together with his family, friends, and general education teachers, ideas were brainstormed for assisting George to become more actively involved in school, to participate in community activities, and to develop meaningful friendships. Some specific areas focused on were helping George's family learn sign language and having George develop more conversational strategies by using a communication book. Next, the discussion identified potential problems that could block these activities such as being too physically aggressive and not following directions. Finally, the group developed an action plan, specifically listing who would be responsible for implementing the ideas generated by all of the participants.

Since last spring, many positive changes have resulted from the MAPS meeting. George is involved in thre general education classes—Life Skills, Home Economics, and Physical Education. During 6th period, George works as an office aide. He now has a full-time interpreter and this has greatly improved his communication skills.

Two additional activities discussed during the MAPS meeting are in process. These are the development of a circle of friends and the opportunity to select and join a club or an extracurricular activity at school. The changes in George's schedule and the support from his friends and family have enhanced not only the quality of his education program but also the quality of his life.

Transition

"I look at transition as the key to the success of special education in the future." This was written by Patrick Campbell, the former Assistant Superintendent/Director of Special Education Division for the California Department of Education.

The federal government is now mandating the "School to Work Transition" for students in special education as part of the Individuals with Disabilities Education Act (IDEA) and the Rehabilitation Act. Transition is an extremely important aspect of a student's education program, including those students who are deaf and blind. Transition has become the framework for describing the ideal adult life of the students in the project.

Too often, professionals have fallen short when planning effective and systematic programs, either during the transition from school to school or from school to adulthood. This is even more apparent in the lives of students who are deaf and blind (Maxion, et al, 1989; Hasazi, 1988; Goetz, Guess & Stremel-Campbell, 1987).

Summary

TOPS has been a very exciting collaborative project. It has significantly enhanced the quality of life of many individuals. Many schools have now endorsed new ways of structuring resources to improve the education of all students. Our preliminary findings can be summarized as follows:

- The use of home inventories has provided tremendous insight into concerns and needs of families and the willingness of parents to be active educational partners.
- Our limited but intensive experience in person-centered planning has convinced us of the value of these approaches in relationship building, developing more meaningful methods of instruction, and balancing the relationship between specialized, generic, and natural support.
- Siblings have shared insights that confirm our most basic

Christine is another student in the Transition Program. She is deaf and blind and utilizes a cane or a cane and sighted guide for travel. Christine has participated in the Transition Program for four years and will soon transition to an adult program. Christine utilizes an object communication system (calendar box) for constructing her daily schedule and routine at school. A cane loop is used for indicating travel/mobility, a bus pass for bus travel, a towel for the exercise club, a chip bag indicates break, and a lunch bag indicates lunch. Other object cues include a wallet for community outings, a swimsuit strap for swimming at the public pool, shopping bag handles for grocery shopping, and a paper towel for bathroom. Christine also has a portable system (a small 3-ring binder with objects) that she carries in a fanny-pack. In addition to the object systems, she uses several hand signs to communicate.

A futures planning meeting was conducted in the spring of 1992. Christine's foster mother, school staff, adult program staff, and a representative from the Helen Keller Foundation participated in the meeting. A videotape was presented to share information about Christine's daily activities. She has worked at a pizza restaurant folding delivery boxes, and at a local variety store pricing items. Her daily routine has included, as part of her transition plan, several work experiences, traveling in the community on public transportation, swimming at a public pool, exercising at a local fitness club, shopping, and preparing simple meals. The video provided important information about successful instructional methods and techniques that would be valuable for her future adult program staff. As a result of this meeting, the transition from school will be smooth without a "break" in service.

assumptions about services, placement on a high school campus, even if it is the home school, and placement in a work environment, even if it is an integrated one, creates the opportunity to develop new relationships and learn new skills, but the placement alone is insufficient for guaranteeing that those things will happen.

- Moving instructional staff from an activity center to an instructional focus requires developing credibility, tact, creativity, teamwork, and patience.
- Using the process of transition to describe an ideal adult lifestyle can lead to a more responsive sense of community and increased collaboration between families and professionals.
- Helping and recruiting peers to consider relationships other than that of a peer tutor requires more of a change in teacher versus peer attitude.
- Developing relationships and friendships between peers takes a considerable amount of time and is endless.

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TRUE OR FALSE? Truly Collaborative Relationships Can Exist Between University and Public School Personnel

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True. Although, the following frequently heard comments might indicate otherwise. From public school personnel:

"Whose dissertation is this?" "What's your budget for subcontracts to schools?" "When do you expect to have your program in place?" "You're the experts, what should we do?" "This is the real world, you know."

From university personnel:

"Implementing this program is minimally intrusive and recording the data will require very little staff time." "The procedures must be followed exactly." "In five years we'll know the results." "The research indicates that..." "We'll need five students between the ages of 8 and 14 who have the label of... but not..." "How stringent is your human subjects review process?"

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Public schools and institutions of higher education perform different functions, operate in different realities, are faced with different constraints, and are reinforced for different outcomes. Individuals in each of these systems, however, share many of the same interests, in other words, addressing the problems facing today's children and youth in public education. Such similarities provide a reason to join together in collaborative partnerships. Differences between the systems can make those partnerships strong, efficient, and effective. If people from each system performed the same functions, knew the same information, and had access to the same resources, there would be no reason to join together. The differences promote learning and create positive interdependence. The individuals and the context of each system have unique and complementary features and contributions. Public schools are charged with direct service responsibility for educating all children and youth ages 5 through 18 with a focus on preparation for desirable post-secondary outcomes. Universities are responsible for inquiry regarding effective practices, dissemination of pertinent findings, preservice preparation of personnel to work in the public schools, and service to the broader education community. Public schools provide the context for the functions of disciplined inquiry and research dissemination as well as field experiences for preservice students. University personnel offer to public schools support in the development and validation of effective practices and graduates prepared to function in the public schools. Ongoing partnerships between schools and institutions of higher education are mutually beneficial.

If the differences between the public schools and institutions of higher education provide the basis for potentially collaborative partnerhips, what makes these partnerships work? The key lies in the use of a collaborative style of interaction. Friend and Cook (1992) defined interpersonal collaboration as "a style for direct interaction between at least two coequal parties voluntarily engaged in shared decision making as they work toward a common goal." The framework used in this article for offering specific strategies and examples of collaborative partnerships between public schools and institutions of higher education is based on the work of Friend and Cook (1992). The shared goal around which we have joined with public schools is the creation of inclusive school communities where all children belong. Our experience tells us that use of a collaborative style of interaction between university and school district personnel increases the likelihood that an innovation such as the inclusion of children with disabilities in the school community will be institutionalized and not fade away when the university involvement is formally ended.

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Characteristics for Collaboration

Defining Characteristics	What Works?	What Doesn't
Mutual Goals	• Develop a relationship • Engage in small scale efforts initially • Shared philosophy	• Engage in a long term commitment without having established a relationship
Voluntary Participation	• Involve key stakeholders • Invite participation	• Work with only one or two individuals on something that will impact many
Parity Among Participants	• Use names, not titles when interacting • Rotate and share team roles (e.g., facilitator, timekeeper, recorder) • Structure ways to facilitate participation	• Call John Jacob, Professor Jacob, instead of John. • Reserve the role offacilitator for a select few
Shared Responsibility for Participation and Decision Making	• Shared perspectives about decisions • Brainstorming before decision making • Balance between coordination of tasks and division of labor • Clear delineation of agreed upon actions as follow-up	• Assuming that tasks must be divided equally and that each party must participate fully in each activity • Placing decision making responsibility with one individual or party
Shared Accountability for Outcomes	• Acknowledging risks and potential failure • Celebrating success together • Embracing failures together,adopting a "learning from failures" mindset	• Trying to determine who to blame • Giving awards to individuals for team efforts
Shared Resources	• Identify respective resources • Having mutual goals • Highlighting the benefits of sharing • Joint decision making about resource allocation	• Protect, not reveal resources • Having no mutual goals and disparate benefits • Use own resources after depleting other's resources

Defining Characteristics for Collaboration

Friend and Cook (1992) conceptualize collaboration as a style of interaction, that is, how individuals or groups work together, not what they do. In addition, they offer six defining characteristics: *based on mutual goals, voluntary participation, parity among participants, shared responsibility for participation and decision making, shared accountability for outcomes, and shared resources.* Each of these characteristics is discussed below with examples related to partnerhips between public schools and universities on the issue of inclusive school communities. Most of the examples are drawn from the collaborative partnership with one school district. The University of Minnesota's Institute on Community Integration and the Forest Lake School District were awarded a three-year grant from the Office of Special Education and Rehabilitative Services, U.S. Department of Education, to assist in operationalizing joint commitment toward returning students with disabilities to the school they would ordinarily attend if they did not

have a disability, and to be active participants in general education classes and school life. The collaborative work represented by this grant, *Achieving Membership in Home Schools for Students with Severe Disabilities*, contributed many lessons. Table 1 presents a summary of facilitating and inhibiting practices, in other words, what works and what doesn't related to each of the characteristics.

Based on Mutual Goals

Having at least one mutual goal is necessary to the foundation of collaborative partnerships. Having a mutual goal energizes individuals to be committed to achieving their goals. Collaboration is hard work. And for most individuals, it involves developing a new mindset as well as a new set of task and relationship skills (Thousand & Villa, 1992).

In working to develop inclusive school communities, a shared philosophy on outcomes for children has led to mutual goals on belonging and membership and often has helped us to get through some of the really tough situations. A principal with whom we have worked reminded his staff many times that what is most important is that Jimmy (a student) belongs in our school, he is a member of our community, he needs to be here to learn and get connected with others in his community, and they with him.

Voluntary Participation

A collaborative style of interaction cannot be forced. One can require individuals to meet and impose a structure intended to facilitate collaborative interactions, but one cannot control how individuals interact with one another. When hierarchical control is removed (e.g., a directive from a superior that an individual must be involved) and instead, an invitation is extended, the desired result of participation is likely to be achieved but the circumstances under which the individual participates (i.e., voluntary, individual choice) significantly changes the type and degree of participation.

Related and equally devastating when it comes to the success of collaborative efforts is the issue of representative participation. Adequate involvement of key stakeholders in collaborative efforts cannot be overstated. This is a lesson that has emerged for us from repeated learning opportunities. In one district we developed a plan for "collaboration" with a district administrator that in reality would impact on the staff members and families of a number of schools, without involving some of those key individuals in the initial development of the plan. Similarly, plans were developed with a large representative group of special educators to significantly change the model of service provision for special education. Lack of participation by general education (the constituency on which an equally substantial impact would be felt), resulted in a plan generated from insufficient diverse input in addition to lack of ownership from key constituents. Conversely, a representative group of general educators was engaged in developing a school's vision and in dialogue about aligning practices with the vision. Inadequate involvement of special educators resulted in a skewed vision of an inclusive community and a lack of shared ownership to the vision. When introducing an innovation or change such as returning and including children with severe disabilities to an age-appropriate class in their home school, there will always be resistance and significant change will take time, but some of the difficulties could be alleviated with an approach that invites rather than dictates collaboration and that adequately represents all key stakeholders in the design and process of change.

Parity Among Participants

Parity among participants is the characteristic essential for collaboration defined as each person's contribution to an interaction is equally valued and each person has equal power in decision making (Friend & Cook, 1992). Using names instead of titles when interacting is one simple facilitator of a sense of parity. Superintendent Jones is known as Bill and Dr. Smith is known as Sarah. Shared leadership promotes parity as well. There is an expectation in collaborative teamwork that there is not one leader but rather a team of individuals who share responsibility for facilitating movement toward a common goal. Collaborative teams are essential to the task of including a student with significant disabilities in his/her age-grade class. The collaborative individual student team meeting is one example of parity at work. The primary support roles (facilitator, timekeeper, and recorder) for these meetings are rotated and shared among all team members. In contrast to many school meetings, family members and paraprofessionals serve as meeting facilitators. Parity assures more effective training experiences also. Because the development of inclusive school communities is new learning for most individuals, our work with school districts has involved quite a bit of training and we have always worked with people in the district both to develop and teach the courses.

Shared Responsibility for Participation and Decision Making

Individuals involved in a collaborative effort are expected to share responsibility for both participation and decision making. Shared responsibility means making a commitment to participate in the activity and the decision-making involved. Shared participation in task completion does not imply that the individuals involved must divide the tasks equally or participate fully in each of the different activities required to reach the goal (Friend & Cook, 1992). In fact, effective collaboration involves a balance between coordination of tasks and a division of labor (Johnson & Johnson, 1987) based on an individual's unique gifts, talents, and interests. Not

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everyone is expected to engage in all tasks to the same degree.

As an example, university personnel often collaborate with individuals from a school district to plan staff development activities and approaches. University personnel may volunteer to draft a needs survey, analyze the results, and develop content outlines based on the information. School district personnel agree to distribute the survey, identify dates and places for training, and secure a representative task force to work with university personnel in finalizing content decisions and instructional approaches. Both university and school district personnel are actively involved in the task even though the different activities may not require equal effort. Even though the tasks each party engaged in may not represent an equal division of labor, there is equal responsibility for the decision making which is part of the staff development effort. In this example that would include deciding the appropriateness of the needs survey, the survey information to be analyzed, the administration approach to be used, the logistics of training, the content of training, and the instructional approaches to be used. University staff usually do more development of and execution of training, but school personnel must devote most of their efforts to six hours per day of direct instruction with children.

Shared Accountability for Outcomes

In other words, we sink or swim together. Whether the outcomes of the collaboration are successful or not, everybody shares in those outcomes. When successful, all share in celebration. When not successful, all share responsibility for that as well. With a collaborative approach, better ideas emerge. No one person is responsible for either successes or failures, which makes individuals involved more willing to acknowledge and learn from their failures, rather than covering them up. This characteristic of collaboration allows individuals to be more willing to take risks and to chance failure. A lack of collaboration results in the counterproductive activity of finger pointing. Two examples will illustrate how issues approached in a collaborative fashion with a sense of shared accountability resulted in outcomes superior to those that would have been possible in isolation.

The first example occurred at the classroom level. Andy was a kindergartener who tended to leave the classroom and the school whenever the mood struck him. This was an extremely serious issue because the elementary school he attended was located on a highway. In fact, Andy did end up on the highway one day near the beginning of the school year. The team immediately came together and began brainstorming. Many ideas were generated and some, understandably, were quite drastic (remember this was a team feeling very scared about Andy's safety). Some of the ideas included: tactilely offensive items on the doorknob such as corn cobs with the husks still on them, a beeper on the door, a beeper on Andy, the door being locked with a latch up at the top of the door (the Fire Department informed us this would be quite illegal, but there were still team members who wanted to do it), a Scandinavian wreath with bells on it for the door. Some of those ideas were implemented with some success initially. However, the eventual combination of ideas that was implemented and worked included: (1) an automatic closer on the door, which also made it harder to open and a chime that went off whenever the door was opened; (2) explicit directions to adults and children who may be going in and out of the door to be watchful that Andy did not wander out; (3) a red alert plan with the code name DEAR which stood for Drop Everything And Run which was to go out over the intercom should Andy wander, in order to alert key adults in the building to run to and out the nearest exit in search of Andy. This plan was shared at a faculty meeting and through written communication to all staff members. Of course, Andy's family was a part of all brainstorming and strategy identification as well. In addition to this reactive plan, a proactive plan was designed. The focus being to increase attention to changing the Kindergarten environment so that Andy wanted to be there and to developing a communication system for Andy so that

when he needed or wanted to leave for a short break, he had a way to make and communicate some choices. This included picture options by the doorway, such as physical education equipment like a bike or ball which indicated a request for a short run in the gym, a picture of the school secretary, indicating a quick visit to the office. The creativity of ideas and the inclusion of the school community as part of the support strategy is one illustration of the power of collaboration and shared accountability. A collaborative approach allowed people to be very open about the problem and enlist many people in generating and implementing some strategies. The broad support would not have happened if only one person had felt responsible for Andy's wandering and its solution. At the end of the school year, in interviews with some of the school's support staff, one of the cooks talked about the DEAR strategy and proudly reported that Andy was doing much better now. During the interview with the school secretary, she talked on and on about how proud they were of *their* Andy. Not only was this collaborative approach effective for Andy, but a sense of pride in Andy and in this staff emerged.

A second example of a shared accountability leading to better outcomes occurred at a systems level and involved the university support configuration provided in a school district with whom we are engaged in a three-year collaborative effort to develop inclusive school communities. The university support structure changed drastically from year one to year two of the program as a result of moving from working with one elementary school to six elementary schools. University support changed from more direct, hand in hand support to one school to more indirect support to the Inclusion Partners (special education support teachers) in each of the six elementary schools and to individual student teams as crises dictated. For many reasons, the support structure did not work well, it was very taxing on the primary university support person and also not extremely capacity-building for the district. However, instead of wasting any time pointing fingers or trying to figure out whose fault this might be, we just got together, defined the problem, generated potential solutions, took those ideas to key players in the district in both verbal and written form, got their best ideas about what they thought made sense, then developed a plan. This plan incorporates people's best ideas, and because they were a part of developing it, there is an investment in making it work and also an openess to let one another know if and when it is not working.

Shared Resources

Individuals engaged in collaborative activities each have resources that can be contributed to reaching the shared goals (Friend & Cook, 1992). This last characteristic brings us full circle to one of the primary points made in the introduction. University and school district personnel perform different functions, know different information, and have access to different resources. This makes the sharing of resources between school district and university personnel especially advantageous. The fact that resources never seem to be adequate makes pooling of resources a motivator for individuals to collaborate. Unfortunately, it can also have the opposite effect of individuals attempting to cling tightly to the resources over which they have control. This fact makes it important to approach discussions of shared resources directly and in a way that highlights the benefits for all involved parties and that keeps individuals focused on their mutual goals.

Emergent Characteristics for Collaboration

In addition to the previous six defining characteristics, Friend and Cook (1992) identify emergent characteristics for collaboration. Emergent characteristics may be present to some degree at the outset of a collaborative partnership but they definitely emerge and grow from successful experiences with collaboration. Each of these characteristics are discussed below with examples provided.

Individuals Who Collaborate Value This Interpersonal Style

It is helpful when those engaging in a collaborative endeavor begin with a commitment to collaboration and a belief that collaboration will result in better outcomes, especially because collaboration does not come easily to many and takes longer, at least initially. However, while a shared commitment and belief in the power of collaboration is helpful, it is not essential for everyone because people can come to value a collaborative style of interaction. It is not easy to find individuals who have a collaborative work style, working alone is quite normative for teachers, administrators, and university personnel. In our partnerships, it seems especially difficult for the adults involved in change, many of whom (like us) did not grow up and have not been socialized in cooperative and collaborative ways of interacting. Most people were trained to work in isolation and, unfortunately, most have received little or no training or experince in the use of a collaborative style of interaction. Given the lack of personal experience coupled with the fact that collaboration is harder and takes more time, at least initially, you can see why people may not immediately embrace the use of a collaborative style of interaction.

Individuals Who Collaborate Trust One Another

Trust does not automatically occur because individuals have made a choice to work collaboratively with one another. Trust is established over time as individuals work with one another, become secure in the commitment each has made to one another, and as inevitable conflicts are resolved and collaborators remain, connected and supportive.

One of the most time intensive collaborative activities schools and universities ever engage in is grant conceptualization, writing, implementa- tion, and evaluation. Some approaches to grant development yield better results than others. The following examples illustrate lessons learned in this regard. One grant was developed primarily with the input of only one district administrator and two university people. A second grant was developed, primarily with the input of a group of district administrators; it included plans for securing the immediate involvement and input of all key stakeholders in developing the action plans outlining our collaborative work with the school districts if the grant were funded. A third grant was written with a school that university personnel had been working with and learning from on an informal basis for more than a year. This proposal truly was a collaborative/collegial effort and was greatly facilitated by a history of working together and the resulting trust and commitment to a shared vision of what we thought schools could be for all children and adults who are a part of the school community. The grant development processes described above were presented in chronological order reflecting our learning along the way! However, despite a lack of collaboration in earlier efforts, a sense of trust was established through ongoing work together, but early work was more strained. Trust is established over and over again as you work with new individuals or new schools in the district.

There is such a strong stereotype that the role of university personnel in schools is not particularly helpful. When we hear, "You're a university person?!" we know we have entered into a new realm of trust and collaboration. That is truly an indicator to us that we are doing something right.

A Sense of Community Evolves from Collaboration

Individuals who use a collaborative style of interaction feel more supported and feel a part of a larger whole. It is this whole that encourages and makes use of individual strengths and minimizes the relevance of weaknesses. One of the most salient outcomes of the process required to achieve inclusive school communities for children is that adults, as well as children, involved in the process learn about and experience a sense of belonging and being valued in a community.

Conclusion

In conclusion, a more specific focus is given to the relationship between effective public school and university collaboration and the institutionalization of change. This is of central importance related to the grant awarding function of the Office of Special Education and Rehabilitative Services. In the absence of collaboration, institutionalization of change is not possible. The characteristics of *mutual goals, voluntary participation, parity among participants, shared responsibility for participation and decision making, shared accountability for outcomes, and shared resources*, provide a framework for the design, development, implementation, and evaluation of projects. In learning more about and having become more successful in a collaborative style of interaction, greater institutionalization of change has also been realized.

In one collaborative partnership supported in part by federal grant money, the following outcomes indicative of institutional change that supports the innovation of inclusive school communities have been realized:

- Children are moved, students with severe disabilities who were once all served in a center based classroom are now being served in their home schools, as members of age-grade classrooms.
- Early childhood programs are all community-based.
- Special educators in the district are able to use Fridays to collaborate with and learn from others—meeting, coteaching, developing materials;
- Job descriptions have been changed. Inclusion Partners are former teachers of self-contained programs whose primary responsibility now is supporting the membership, active participation, and learning of students with disabilities who are members of age-grade classrooms.
- Summer school is now integrated with the district's school-age child care program.
- Special educators are beginning to collaborate with one another at the building level and provide non-categorical special education support when it makes sense to do so.
- An elementary principal was recently heard to say, "He is our student, we need to figure out how to make it work."

These outcomes have resulted from a three-year university/school district partnership. In this partnership, many mistakes have been made. Upon reflection, we believe that our commitment to a collaborative style of interaction is what, in the end, has insured positive outcomes for those children included in their school community and has solidified a district commitment to insure those same outcomes for children it may serve in the future. ♦

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AN OSERS News In Print SPECIAL FEATURE

Early Childhood Community Integration: *An Option for Preschool Special Education*

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Photo: David Snyder

The move toward integrated preschool special education programs is not surprising given the abundance of research and demonstration models that have collected data supporting the benefits of such programs (Guralnick, 1990; McLean & Hanline, 1990; Odom & McEvoy, 1990). These data were derived from a conceptual base which emphasizes the social, ethical, educational, and legal reasons for the development of programs that integrate young children with disabilities and young children without disabilities (Bricker, 1978). As a result, the provision of integrated preschool special education has been cited as a quality indicator of service delivery models for this age group (McDonnell & Hardman, 1988; Strain, 1990). One method to accomplish this has been to provide intervention services to young children with disabilities within community early childhood programs (Bruder, Sachs & Deiner, 1989; Hanline, 1990; Templeman, Fredericks & Udell, 1989). Referred to as **mainstreaming** (Odom & McEvoy, 1990), this special education option represents the integration of a child into a more normalized setting than is usually provided within segregated sites.

The Infants and Toddlers Program (Part H) of the Individuals with Disabilities Education Act (IDEA), a grant program to assist states in developing and implementing early intervention systems, requires that, to the extent appropriate, early intervention services must be provided in the types of settings in which infants and toddlers without disabilities would participate. Part B of IDEA requires that children with disabilities receive special educa-

tion and related services to the maximum extent appropriate in the regular education setting, sometimes referred to as the least restrictive environment (LRE). The LRE provision for special education services for children ages three to five has been further clarified to suggest that one program option for preschoolers could be special education placement within a publicly or privately funded program for children without disabilities. In spite of these policies, this program option is not readily available for preschool age children eligible for special education. There seems to be many reasons for this, including the lack of a philosophical commitment for integration, the lack of appropriately trained staff, and a lack of a cost structure to support integrated options within community settings.

Background of Project

The state of Connecticut is similar to many states in providing special education services to preschool age children under the Individuals with Disabilities Education Act. These services have been provided to children from age 2.8 since 1980 and Connecticut's 169 local education agencies (LEAs) are responsible for services implementation. However, since preschool children without disabilities are not eligible for free appropriate public education in Connecticut, opportunities for integration have been limited.

Children with disabilities under the age of three can receive early intervention services from a variety of agencies within Connecticut. The State Department of Mental Retardation (DMR) provides services to the largest number of eligible infants and toddlers (approximately 500). In 1987, DMR decided to disband all segregated infant-toddler center-based programs and replace them with the provision of early intervention services in places where typical children normally participate (e.g., day care programs, recreation programs). Home-based services are also an option for families.

The Pediatric Research and Training Center at the University of Connecticut School of Medicine provided technical assistance for this change in service delivery site for DMR sponsored programs. One of the outcomes resulting from the development of this service delivery model was the resistance of parents to segregated preschool programs for their children after transitioning from an integrated DMR program. As a result, many of Connecticut's LEAs were interested in expanding integrated program options for their preschool children with disabilities.

The Early Childhood Special Education Community Integration Project (hereafter referred to as the Community Integration Project) at the Pediatric Research and Training Center was funded by OSERS' Handicapped Children's Early Education Program in 1988 to assist LEAs to develop integrated options for preschool-age children with disabilities. In particular, the project focused on the use of community early childhood programs as delivery sites for preschool special education. This model replicated the option DMR was providing to infants and toddlers. The project had five objectives and each will be described.

(1) To develop procedures for choosing community early childhood programs in which special education and related services could be delivered to preschool children with disabilities. To accomplish this objective, the project developed and used a site selection tool that contained questions about the overall environment of the community placement. The Nursery School/Day Care Profile was designed by the project staff to assist them in gathering basic information about the content and quality of the community-based early childhood programs (day care/nursery schools) that were interested in participating in the project. The profile consisted of both an interview section and observational section. Table 1 contains the variables addressed by the profile. An adaptation of this tool was designed for parents to complete as they became involved with the selection of the community program placement.

(2) To provide training to those involved in the delivery of preschool special education and related services to the child within the community early childhood programs. This objective included the assessment, implementation, and evaluation of training competencies unique to each audience involved in the project. The audiences included families, special education and related services staff, and community program staff.

Variables Measured on the Preschool Profile

- Population Served *(age of children, size of classes)*
- Licensing Requirements
- Staffing (experience, training, ratio to children)
- Philosophy
- Criteria for Admission
- Finances and Cost for Attendance
- Policies and Procedures
- Experience with Children with Special Needs
- Curriculum
- Environment
- Daily Routines
- Adult Child Interactions
- Family Involvement

(3) To provide early childhood special education and related services to children within an early childhood program. The project staff assisted the local education agency (LEA) and community program with the actual design and delivery of the child's Individualized Education Program (IEP). The instructional programs were developed through a team process that included both LEA and community program staff. These interventions were designed to be implemented within typical routines and activities emphasizing age appropriate activities and social interactions.

(4) To evaluate the effects of special education and related services delivered to children in early childhood settings. The actual implementation of special education and related services in early childhood settings was continuously monitored for decision-making purposes. As a part of the evaluation design, a battery of assessments was implemented on both the children and their families. The assessments measured children's developmental status, social and play skills, and level of engagement within the environment. The parent assessments measured the family's perception of their child's developmental status, their attitude toward integration and the integrated placement, and their use of informal social support and resource networks. Data were also collected on program and community status during the implementation of the project.

The assessment results were used to formulate both the instructional objectives on the IEP and the type of training to be provided to staff and families. Beside the summative use of these data to describe and measure the participants' progress in the project, the establishment of a structured assessment protocol for families and children provided a model for the special education staff of the participating LEAs. Table 2 contains a listing of the measures used within the project.

Evaluation Design for Early Childhood Special Education Community Integration Project

Family Status	Child Status	Program Status	Community Status
Demographic Information; Expectation Questionnaire; Inventory of Social Supports; Community Resources Checklist; Minnesota Child Development Inventory; Consumer Satisfaction.	Demographic Information; Battelle Developmental Inventory; Preschool Language Scale; Engagement Check; Type and Location and Frequency of Special Services.	**1. Staff:** Demographic Survey; Expectation Questionnaire; Pre/Post Tests; Experience; Consumer Satisfaction. **2. Community Program:** Early Childhood Environment Rating Scale; Nursery School/Day Care Profile. **3. LEA:** District Profile; Program Review.	Administrator's Survey (LEA); Community Program Survey.

(5) To develop policies and procedures for local education agencies providing preschool special education and related services within community early childhood settings. Each LEA that participated in the project completed a program review. The Program Review was an adaptation of the Comprehensive Program Review developed by the National Early Childhood Technical Assistance System (NEC*TAS). The Review was designed for use as both a self-assessment tool for districts, and as an assessment instrument for project staff in their work with district personnel. This instrument specified areas of program policies and procedures related to the successful implementation of early childhood special education programs. Ongoing input on policy development was also obtained from participating program administrators and state agency representatives.

Demonstration Procedures

The families of preschool age children who were eligible for special education and related services within the participating LEAs were advised of all service delivery options including community settings as part of the Planning and Placement Team and IEP process. If a community placement was recommended by the LEA special education team (including parents), the Community Integration Project became involved with the child.

The first issue the project addressed with the participating LEA staff and family was the identification of a day care or nursery school appropriate for the child's needs. To be deemed appropriate, the program had to meet the following criteria: operate under a state license; contain a grouping of children of the same chronological age as the target child; be located within the same town in which the child resides; be accessible to adaptive equipment; and be willing to participate in the project. An environmental inventory was also conducted at the site. After a site was chosen, the project staff conducted a training needs assessment with the family, special education staff, and the community early childhood program

staff in regard to the child's special education needs. This needs assessment provided information from which both individual and group training was developed. A training contract was then developed between the LEA and project staff. The contract delineated the content, type, and frequency of training and technical assistance which were to be provided to support the placement of the child within the community setting.

The training was provided through a variety of modes depending on the content, objective, competencies, and audience preference. All training was competency based, and most occurred through activities and on site applications of consultation and teaching techniques. In addition, the family training component of the project was designed to enable parents to be active participants in the planning of their child's integrated program. Project staff served as consultants and resources to the families of the children enrolled in the project.

Once the child began to attend the community program, a number of outcome measures were implemented on the child, the family, the program, the staff, and the other children and families within the setting. Ongoing training and technical assistance were delivered as specified by the training contracts and ongoing evaluation of the training occurred.

The project was committed to ensuring that the child participated in all activities within the community program with specific educational goals and objectives incorporated into these activities and routines. Support staff, materials, curricula adaptations, and, when appropriate, direct services were provided to the community program by the preschool special education staff under project direction. Over time, the special education staff provided more consultative services to facilitate a transdisciplinary service model and fewer direct services to the community program. Likewise, in most cases the demonstration project staff modeled intervention techniques to both the special education and community program staff, and over time this provision of direct service by project staff was faded out.

Project Results

Child Change. During the project, children were assessed a minimum of every six months. During the second and third years of the project, the children made statistically significant gains using age equivalent scores on all domains (and the total) on the Battelle Developmental Inventory (BDI) ($t = 6.45$; $p < .001$ for total score), and the Preschool Language Scale (PLS) ($t = 2.95$; $p < .01$). Since the use of gain scores has been justifiably criticized (Hauser-Cram & Wyngaarten Krauss, 1991), Proportional Change Indices (Wolery, 1983) were also computed on these data. The results suggested a mean index of change for the 16 participating children during year three on the BDI total score as 1.09 and on the PLS as 1.66. These indices suggest that the mean rate of development during intervention was 1.09 (total) and 1.66 (language) greater than the rate of development they showed prior to intervention. Additionally, the children also demonstrated an increase in their total engagement scores. In particular, this change reflected an increase in the engagement with peers category and a decrease in the engagement with objects category. Data were also taken on the types of support provided to children within the integrated sites.

Family Change. The families did not demonstrate statistically significant change on the Community Resource Log nor the Inventory of Social Supports. This is not surprising due to the fact that the parents represented a group of intact (all but two were married), well educated (all had graduated from high school, 18 had at least two years of college), and employed individuals.

During participation in the project, the families did demonstrate a slight increase in use of community resources. Of greater interest, however, were the responses of the families on the Inventory of Social Support. For example, none of the families used formal services as support in such areas as help with child care, questions about child rearing, encouragement when things get difficult, acceptance of child regardless of behaviors, and fun and relaxation. The supports consistently used for these areas were listed as myself, spouse, parents, or friends. The formal support service of early intervention was identified by about half the families for use in the areas of helping with hassles with agencies when needs/wants are not met and help in learning about services. The parents also demonstrated an increase in their positive responses and a decrease in their negative responses on the expectation questionnaire. Lastly, the parents' scores for their children on the Minnesota Child Development Inventory was highly correlated ($r = .88$ for total scores) to the scores on the professionally administered assessments (BDI, PLS), when using both raw scores and age equivalent scores for both individual domains and the total.

Program Change. Selected information was collected on the early childhood community programs that participated in the project. These programs demonstrated significant changes in their total scores on the Early Childhood Environmental Rating Scale (ECERS) during both year 2 and 3 ($t = 3.28$; $p < .008$). The participating LEA programs also demonstrated changes in policy as documented in their program review. All program staff increased their scores on the positive outcome statements on the expectation questionnaire, and decreased their scores on negative outcome statements. This suggested an overall increase in positive expectations for children as a result of integration.

Community Change. Since the Connecticut Department of Mental Retardation has been providing group intervention services within community programs for children birth to three with disabilities, there has been a steady increase in the number of children who transition into LEA integrated special education services at three. In 1991, 53 percent of the DMR "graduates" of integrated birth to three services continued to receive special education services from their school systems in programs that also served nondisabled peers. This number represents an increase from 26 percent from the first year (1988) that DMR provided services in community programs (L. Goodman, personal communication, September 18, 1991). Likewise, the Connecticut State Department of Education has been providing preschool incentive dollars under P.L. 99–457 (Part B) to districts to ensure a continuum of available LRE options. Since the inception of this program, there has been a dramatic increase in the number of preschool age children receiving special education in programs also serving nondisabled peers (K. Halverson, personal communication, November 12, 1991).

Photo: David Snyder

Discussion

The Community Integration Project was successful in facilitating the delivery of special education and related services to children with disabilities who attended existing community early childhood programs. During the refinement of project objectives, four interrelated components were identified as necessary to the successful expansion of integrated special education preschool programs. These will each be separately discussed.

Service Delivery

The implementation of "state of the art" service models for young children with disabilities remains a challenge to many LEAs. Many of the service innovations developed within the past 10 years are just beginning to be systematically implemented within early childhood special education programs. These innovations include team-based decision making, cross disciplinary assessment protocols, IEPs containing age appropriate, functional, transdisciplinary goals and objectives, instructional programs which are implemented within typical early childhood routines and activities, the use of instructional and assistive technology, and the delivery of related services within classroom activities. Family involvement within the development and delivery of services also remains an elusive goal for many. Nonetheless, the results of this model demonstration project suggested that the delivery of such innovative practices can be as effectively implemented within integrated early childhood settings as within segregated settings.

Training

The project's main emphasis has been training. The type of training initially requested by LEA staff consisted of basic early childhood special education principles and techniques. Once training on these topics was implemented, a second emphasis of LEA staff training focused on team development and consultation techniques to facilitate learning activities with the community program. The community program staff requested a thorough overview of the legal and programmatic components of special education. Families requested training to prepare them to become integral members of their child's intervention team.

Evaluation

The evaluation design allowed staff to implement a battery of measures on children, families, and program staff. The collection of this information allowed project staff the opportunity to share with LEA staff, families, and community program staff data on a number of program features that impinged on the effective implementation of this model. These features included the quality of the community program environment, the staff (both

LEA and community) backgrounds, qualifications, attitudes, and identified training needs, the families' involvement with community resources and informal support systems, the families' perceptions of their child's needs, the actual delivery (frequency, type, and outcome) of special education and related services, and the effects of support and training activities.

Policies and Procedures

The initial intake data on the district profiles suggested that six of the LEAs had policies and procedures for their preschool special education programs. However, none had policies and procedures on options for the provision of special education and related services within non-special education settings. All targeted this area as one to focus on during project implementation.

Conclusion

The experiences of the Community Integration Project support the delivery of special education and related service to preschool children with disabilities within community early childhood programs. However, there are barriers that exist within school systems inhibiting the implementation of such service delivery models. These barriers include philosophy, funding, and training.

Philosophy. Fairly recently, the paradigm of early intervention has shifted from a stimulation and/or remediation program into one which is family directed, community based, and integrated. While components of the old model can be incorporated into the design of more responsive systems of intervention, many have yet to conceptualize how these new models can be implemented.

One solution to the philosophical dilemma may be to shift the early childhood special education paradigm into a model of inclusive programming for all young children (Salisbury, 1991). This model is one which was embraced by the Community Integration Project, and which was found successful for the participating children and families.

Training. The philosophical shift required by the changing paradigm of early childhood special education is the easiest component of change. The implementation phase of this paradigm shift presents many challenges since it requires an intensive commitment by the participants to learn new roles. For many, the training will encompass a new body of knowledge. This will include content areas such as the development of social competence within children; the design, implementation, and evaluation of functional intervention targets taught within normal early childhood routines and activities; and collaborative consultation skills.

A solution to the training issue is that preservice personnel preparation models be updated to include the implementation of early intervention within community settings. Currently, personnel preparation programs reflect certification requirements covering a broad age range. A second and related solution would be the requirement of ongoing in-service participation unique to early childhood for those currently providing services.

Funding. While many in support of community based integrated early childhood special education programs argue the cost effectiveness of this type of program model, none of our participating districts chose to use cost effectiveness as the reason for implementing the model. This was summed up by a district administrator in the project when he said, "The issue shouldn't be cost per se, but quality in relation to cost. If an integrated model will result in better child outcomes, we can't afford not to provide it."

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